COTA
For older Australians

'Even paradise is not paradise if you are lonely'

Focus group participant

Mental health and wellbeing during the COVID-19 Pandemic:

The lived experience of Australians aged 75 and over

PROJECT REPORT

February 2023

About COTA Australia

COTA Australia is the peak body representing the almost nine million Australians over 50. For over 70 years our systemic advocacy has been improving the lives of older people in policy areas such as aged care, health, retirement incomes, and more. Our broad agenda is focused on tackling ageism, respecting diversity, and the empowerment of older people to live life to the full.

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COTA Australia acknowledges the Traditional Custodians of country throughout Australia. We recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples, and their continuing connections to land, sea and community. We pay the utmost respect to Elders past, present and future.

Acronyms and key terms

AIHW is the Australian Institute of Health and Welfare, an independent Australian government agency working with health and welfare data.

CALD is an acronym for Culturally and Linguistically Diverse. It encompasses people who were born overseas, have a parent born overseas or speak a variety of languages. The Australian Bureau of Statistics (ABS) defines the CALD population mainly by country of birth, language spoken at home, English proficiency, or other characteristics (including year of arrival in Australia), parents' country of birth and religious affiliation.

CO.AS.IT. Italian Assistance Association is a national service that provides home care, respite care, volunteer visitation and social support for members of the Italian speaking community.

CVS is Community Visitors Scheme, a service which matches older Australians with volunteer, trained community visitors for home visits.

MCWH is Multicultural Centre for Women's Health, a Victorian community-based, not-for-profit health promotion organisation led by, for and with women from migrant and refugee backgrounds.

NMHC is Australia's National Mental Health Commission, which provides evidence and advice on ways to improve Australia's mental health system. The NMHC is the funding body for this research.

Older Australians are, for the purposes of this research, Australians aged 75 and over.

Primary care is used in this report to denote the range of frontline services that have contact with older Australians.

Primary health care encompasses the services that provide entry level to the health system. It includes a broad range of activities and services, from health promotion and prevention to treatment and management of acute and chronic conditions.

PHNs are Primary Health Networks, independent organisations funded to coordinate primary health care in 31 regions nationally.

Executive summary

In October 2021, COTA Australia began a research project with the Australian National Mental Health Commission (NMHC) to gauge how the COVID-19 Pandemic affected the mental health and wellbeing of Older Australians. The aim of the research was to inform the National Pandemic Response Plan.

We asked to hear directly from people aged 75 and over about how they managed during the Pandemic and lockdowns, and to what extent, if at all, their mental health and wellbeing were affected. We surveyed over 1,000 older Australians, conducted in-depth interviews and focus groups, and received written submissions.

We heard that the COVID-19 Pandemic and lockdowns have had profound impacts on the mental health and wellbeing of people aged 75 and over.

These impacts have manifested in different ways (including loneliness, fear, loss of social connections, worsening mental health and reduced physical activity, leading to cognitive decline). Some symptoms were evident to varying degrees even among those who said that their mental health was 'not affected.'

While a number of older Australians reported experiencing some positive impacts and focused on narratives of resilience and stoicism, they too were affected by loneliness and isolation, feelings of fear and loss of purpose.

Particularly affected were older Australians in residential aged care, people with disability, people living with dementia, those with caring responsibilities, older people from culturally and linguistically diverse (CALD) communities and those with pre-existing mental health conditions.

COTA Australia's research suggests that the COVID-19 Pandemic has exacerbated pre-existing inequalities, created new ones, and heightened the impact of ageism on the lived experience of older people during the Pandemic. These impacts are likely to be long term, and will require localised, iterative, and committed responses to address them.

We need to ensure that the strategies that people aged 75 and over asked for – strong social connections, the right information, access to social support and services, age-informed mental health expertise, and engagements with community-based organisations – are in place, adequately funded and accessible to all.

We also need to reiterate the right of older people to adequate and appropriate mental health services, and that this should inform any crisis response.[1]

Recommendations summary

1. **Fund adequate and appropriate support, education and engagement for priority groups**, particularly older people with pre-existing vulnerabilities to mental ill health, those in residential aged care, from CALD communities, and people with caring responsibilities, including formal and informal carers.
2. **Improve messaging and communication for older Australians**, including advice on how to manage mental health and wellbeing, and move beyond a focus on physical wellbeing and impacts of the Pandemic.
3. **Increase accessible mental health services and preventative measures that are informed by an understanding of ageism, ageing and gerontology**. Explore models that promote and normalise mental health among older Australians. Any education and promotion of mental health and wellbeing should be accompanied by adequately funded and staffed services. Digital and online services are not always accessible to older Australians.
4. **Target strategies at each level of government, including local government**. Develop and implement an Older Person's Mental Health Strategy that can inform the National Pandemic Response Plan. This strategy should include a social and mental health education campaign for older people and work with local government to provide a balance between local responses and national oversight.
5. **Strengthen, fund and expand successful community engagement initiatives and ways of embedding community and social connections**. Community-based strategies and interventions were crucial to the wellbeing and mental health of many older Australians, and successful models should be identified and funded to continue their work in diverse settings.
6. **Prioritise staff training and education in mental health awareness for people providing care and services to older people**. A comprehensive Pandemic Response Plan must encompass strategies to support workers and carers during times of crisis. A skilled, professional workforce that delivers appropriate care must also receive the support to recover from any vicarious trauma.

What our research is about and why it is important

In June 2021, the NMHC funded ten projects investigating the impact of the COVID-19 Pandemic on different communities in Australia. This project was selected as part of that process to investigate how the COVID-19 Pandemic impacted the mental health and wellbeing of Australians aged 75 years and over.

During times of national crisis, this segment of older Australians is likely to be experiencing a high incidence of frailty, disability and social isolation and has different experiences and needs to those of older Australians aged under 75.[2]

What did we want to find out?

This research project asked:

- What mental health and wellbeing challenges did people aged 75 and older encounter during COVID-19?
- Were these challenges exacerbated by Pandemic-related restrictions? If so, how?
- What are the immediate and ongoing impacts of these on their quality of life?
- Were government communications useful in building confidence/coping capacities and reducing (or otherwise) levels of anxiety?
- What are the strategies and coping mechanisms that enabled people aged 75 and older to better manage their mental health and wellbeing?
- What are effective ways to maintain and/or foster mental health and wellbeing among older people, especially during times of national crisis?

What did we do?

We collected data through both quantitative and qualitative methods, comprising online and telephone surveys and interviews, face-to-face interviews and focus groups and submissions.

We used a mixed methods approach, comprising:

Data sources

1119 responses received Australia-wide	An online survey of 34 questions.
32 focus group participants	Targeted focus groups with members of five CALD communities in the following languages: Italian, Greek, Cantonese, Mandarin, and Egyptian Arabic
27	Submissions via **mypandemicstory@cota.org.au** and webform
15	In-depth interviews

What did we find out?

Finding 1: Everyone was affected

Everyone was affected, even older Australians who told us their mental health and wellbeing ‘stayed the same’ over the course of the Pandemic and lockdowns. When asked to describe their mental health during the Pandemic:

- **64%** reported their mental health **stayed the same**
- **3%** reported their mental health **improved**
- **14%** reported their mental health **worsened**
- **4%** reported experiencing mental ill health **for the first time**
- **15%** reported their mental health **fluctuated regularly**.

Of those who reported adverse impacts on their mental health:

- **64%** had a pre-existing mental health condition
- **42%** reported their mental health worsened during the Pandemic
- **20.5%** strongly agreed, and 48% agreed that these impacts will be long term
- **8%** thought about suicide
- **66%** were women.

- Loneliness and distress arising from social isolation and separation from friends and family were the key impacts. All groups identified these impacts as the worst of the Pandemic. Those who identified as having a pre-existing mental health condition were the most affected, as were people living in residential aged care and those with caring responsibilities.
- Older Australians from CALD backgrounds also reported similar impacts, but there were differences. They spoke of not receiving adequate information, of relying on family for translation and support, and of fearing that their race or cultural background, combined with their age, made them more likely to be ignored by the health system. For example, in one focus group, some people feared they would not receive appropriate treatment because of their ethnicity and regretted not having returned to their homeland before any lockdowns.
- We heard that physical decline through lack of activity and its cognitive impacts affected the mental health and wellbeing of older people.
- Bereavement and grief due to losing a loved one during the Pandemic and being unable to mourn appropriately also affected the mental health and wellbeing of older people, particularly those who lost spouses during lockdown periods.
- Many older Australians who are carers or have informal carer responsibilities struggled without any respite. Many home support services stopped or decreased, leaving carers isolated and unsupported, with detrimental impacts on their mental health.
- There were gendered differences. Older women were more likely than older men to report their mental health worsened during the Pandemic, fluctuated regularly, or they experienced mental ill health for the first time.

Finding 2: Information provision was not adequate

A strong theme was the call for better, consistent information about lockdowns and self-care during the Pandemic. While many older Australians were happy go online to receive information, many preferred television, print and other media. Others found online information inaccessible.

This issue was exacerbated for CALD communities who relied on information from their country of origin for advice, even though this was not specific to Australian contexts. For example, older people of Italian backgrounds spoke of the distress caused by seeing the triaging of older people in Italy and of nursing homes being abandoned and fearing that this would happen to them in Australia. This fear was compounded by the lack of accessible information in Australia. People called for clear, consistent information on what do and how to do it, in formats that were useful and relevant: *'You can't assume the message is getting through because you put a translated pamphlet on a website. Who reads that?'* (interviewee)

Finding 3: There is a lack of information and knowledge about, and engagement with, the formal mental health system

The majority (89%) of people whose mental health was affected by the Pandemic did not use mental health services, as they:

- 'did not need them'
- could not find appropriate services
- could not afford them
- agreed that these services did 'not understand the needs of older people'.

The language of mental health is also important. Older Australians, even those who considered themselves unaffected by the Pandemic, described themselves as living with 'worry' and 'stress', of experiencing sadness, loss, lack of sleep and appetite, of distress, but rarely 'depression' or 'anxiety', for example.

The stigma associated with mental illness and seeking support for mental ill health was also raised in focus groups and interviews, and identified as a barrier to receiving support. Older Australians emphasised resilience and 'getting on with it.'

In focus groups with CALD communities, the concept of mental health and wellbeing was explained in language or discussed in ways that mitigated the perceived shame of mental illness, rather than translated directly.

Improving mental health literacy needs to be developed in collaboration with targeted communities. Strategies must be trauma-informed, and strengths based. A 'one campaign fits all older people' approach is not useful. Instead, these must be co-designed with each community, and address the stigma associated with receiving help for mental ill health.

Finding 4: Older Australians relied on primary care, including community-based support, GPs and trusted service providers

Many older Australians engaged with services at this primary level of care during the Pandemic, and these supports were instrumental in people remaining well.

Most people were unaware of mental health support services for older Australians; others found them inaccessible (due to cost and location) or too difficult to access when they moved online or demonstrated a limited understanding of the impacts of ageing and mental health.

GPs were the preferred initial contact for many older Australians when needing care or support for their mental health. Community-based groups, some home care providers, faith-based organisations and those working with older Australians from CALD backgrounds are just some examples of the trusted service providers who mobilised to deliver support during the Pandemic.

However, this does not diminish the importance of providing mental health services and supports, particularly those that meet the needs of, and are accessible to, Australians aged 75 and over, in all their diversity.

Finding 5: Protective factors are linked to social and economic determinants of wellbeing and health

Older people with strong social connections (family, cultural, friends, faith-based), adequate support, housing and financial security fared better during the Pandemic. Lockdown measures exacerbated pre-existing vulnerabilities in communities and for individuals.

Finding 6: There were also positives from the Pandemic

Just over a third of survey respondents reported that the Pandemic had some positive outcomes, including:

- more time to spend on activities and hobbies
- improved relationships with family and friends
- increased resilience
- gratitude for health and wellbeing.

A small proportion of survey respondents (3%) noted that their mental health improved, although this was not reflected in focus groups or interviews.

Gender differences

Of survey respondents, 58% identified as female and 41.6% identified as male.[3]

Men

Older men were significantly *more likely* than women to:

- live with a spouse or partner
- live with a family member
- report their mental health was unaffected during lockdowns
- rate their current mental health as excellent
- report that during periods of lockdown they felt well and that their routine did not change during lockdowns.

Older men who lived with a spouse were less likely to report being affected by the Pandemic, even if they had caring responsibilities for that spouse.

They were significantly *less likely* than women to:

- be living independently alone
- be receiving care packages or support
- use video conferencing, Skype and be active on social media as a way of staying connected
- use telehealth or online services
- stay connected with friends or family during periods of isolation
- report they enjoyed having more time to themselves during lockdowns.

Women

During lockdowns, older women were significantly *more likely* than men to experience:

- loss of confidence
- mood changes
- feeling isolated and lonely
- living with fear
- loss of appetite and sleep
- distress by loss of usual activities and volunteering
- separation from family as the worst impact.

More older women (42%) than older men (24%) reported that that the Pandemic had some positive outcomes. Significantly more women than men also reported they enjoyed having more time to themselves and having more time to do things they enjoyed.

Older Australians who reported their mental health worsened during the Pandemic and lockdowns

One third of older Australians reported their mental health was adversely affected by the Pandemic and lockdown measures.

88%	did not receive support from a mental health professional or mental health service
20%	reported experiencing financial distress as a result of lockdowns and that this affected their mental health and wellbeing
30%	felt more isolated when services moved online
62%	relied on a community or health services visitor to check on them during lockdowns
20%	had no one to talk to during periods of lockdowns
61%	noticed mood changes
22%	struggled with the cessation of their usual services and support systems
61%	became less physically active
25%	lost their sense of purpose
8%	could not get the help they needed (compared to less than 1% of those whose mental health stayed the same)

16% of older Australians who experienced mental ill health for the first time in their lives had lost someone close to them to COVID-19

Prior to the Pandemic

- Older Australians whose mental health worsened were more likely to be living with an untreated, pre-existing mental health condition.
- Older Australians whose mental health worsened were more likely to report being lonely, unhappy with relationships and connections, feeling isolated and less likely to have participated in local council, community and volunteering activities.

Opportunities from our research

Aboriginal and Torres Strait Islander communities

Any pandemic or disaster response must take as central the strengths, capacities and resources of Aboriginal and Torres Strait Islander people. Our survey had two respondents who identified as Aboriginal or Torres Strait Islander. One commented that the survey could not capture the support offered by their community and the strong role communities played in mobilising to look out for Elders. The specific impacts on First Nations communities cannot be collapsed into research with non-Indigenous Australians. This necessitates further engagement and culturally safe and appropriate research, particularly in the light of 2021 Census data that indicates numbers of older First Nations people are increasing.

Importance of connections for older Australians

- This research challenges the assumptions about all older people being lonely and socially isolated, even before the Pandemic and lockdown measures. Instead, many people identified that they had as much social activity and connections as they wanted, participated in regular activities and volunteering, relied on strong connections and looked out for those who were not as connected.
- People suffered when these connections and supports were disrupted. Further work needs to be done to understand whether these connections have been reinstated, which groups have struggled, what has facilitated these reconnections and in which contexts people need targeted support.

Ageism, age and further research

- Older people are consistently identified as being the least affected by lockdown measures.[4] While this speaks to the resilience of older people, it does also raise questions about ageist assumptions informing research, and the engagement of older people with the formal mental health system and diagnosis of mental health conditions. It is also the group most likely to be prescribed medication rather than other therapies; this has implications for how we understand mental health and wellbeing in the lives of older people and renders comparisons with younger people simplistic.

- ABS data suggest that people aged 65 and over are less likely than other age groups to be diagnosed with a mental illness, yet 12% of women aged 85 and over have received such a diagnosis.[5]
- Research is needed that breaks down what is happening at each age cohort and what is specific to each age group, so that age-related understanding of the Pandemic impacts on mental health is not limited to comparisons between younger and older people.

Knowledge translation

- Research highlighted the importance of community engagement as a preventative and educative mental health and wellness measure, with many opportunities for the NMHC to focus on knowledge translation. Questions to consider answering include ‘How will we get relevant and appropriate information to older people about resilience, support available and how to look out for their mental health?’

Older Australians we could not reach

- There is a need for proactive engagement with groups that were hard to reach – for example, older people who may be isolated and do not participate in religious, community or other groups, do not have an online presence, and receive limited, if any, home care support. (See Appendix 2)

Recommendations

1. Vulnerable older Australians should be identified and prioritised in the National Pandemic Response Plan. This entails funding adequate and appropriate support, education, and engagement for priority groups

Identify strategies to address their specific needs as they emerge. Ensure that during times of disaster and emergency, tailored activities and resources that meet their mental health and wellbeing needs are delivered. Priority groups should include, but are not limited to:

Older people with pre-existing or ongoing mental health conditions

The Pandemic and lockdowns had an adverse impact on older people who had experienced mental ill health prior to the Pandemic and they needed to be recognised as a priority group. Many did not receive ongoing care and support and relied on medication through general practitioners, considering that the formal mental health system does not understand the needs of older people, is costly and hard to access. They also experienced more isolation and loneliness. A Pandemic Response Plan should prioritise engagement with this cohort.

- Services that are in contact with older people in any capacity should have co-developed risk registers and individual disaster plans for each consumer that can be implemented in terms of crisis.

People in residential aged care

People in residential aged care should be identified as a priority group. While there is a need to find a balance between safety and letting people visit for social connection, denying visitors to residential aged care is in contradiction of quality standards.

Respondents repeatedly asked for visitors to be allowed during times of crisis, and restrictions to be lifted.

- Ensure that people in residential aged care have accessible, individual means of communication (at least a landline in each room).
- Ensure that residents have adequate connections within and with the wider community and foster and strengthen these.

The understanding of mental health varied from facility to facility, provider to provider and staff member to staff member. A focus on crisis management seemed to override other issues:

- Staff training and education in mental health awareness for people providing care and services to older people should be prioritised.
- Implement mental health measures and recommendations from the Royal Commission into Aged Care Quality and Safety.

Older people living with disability

People living with disability reported higher levels of worsening mental health during the lockdowns, and diffculty in accessing services and support to continue living independently and maintain social connections.

Older people from CALD communities

A national Pandemic Response Plan must build on programs that support CALD communities to ensure they can deliver support and services to those aged 75 and over.

Older Australians from CALD communities face specific barriers in accessing mainstream mental health and wellbeing support that go beyond language requirements. During the Pandemic and lockdowns, organisations that work with CALD communities mobilised to provide care, support and pre-emptive services to mitigate the potential impacts of the Pandemic.

- **Expand effective models that utilise existing connections**.

  There are great models where the use of trusted community connections/leaders could be adapted to provide targeted, appropriate, and relevant support for communities. Examples include the bi-lingual and bi-cultural programs provided by the Multicultural Centre for Women's Health (MCWH), the Hallam community group and CO.AS.IT. These organisations have existing relationships with their communities and could be strengthened and funded to pilot further place-based programs on mental health and wellbeing in language with older people, specifically those aged 75 and over.

- **Organisations such as the MCWH** should be funded to provide outreach and engagement with people aged 75 and over from CALD communities, their families and the people who care for them. Their model of bilingual health education is applicable to mental health education.
- **Ensure communication is culturally and age appropriate**.

  Engage with CALD communities to co-design and co-develop appropriate and targeted communication and messaging strategies about mental health in times of disaster. Translated documents on a website are not adequate. Resources that are engaging, age and culturally appropriate as well as activity based to foster connections are needed.

Older people with caring responsibilities

- Ensure that those with caring responsibilities receive adequate support and respite to continue with their roles without it affecting their mental health. This could be outreach by local government and home care providers.
- Explore how My Aged Care can work to provide information and referral to support people's mental wellbeing and that of carers, both formal and informal.

2. Improve messaging and communication

Older Australians asked for clear information and direction on staying safe and on how to manage mental health and wellbeing during times of national emergencies such as pandemics. The perceived lack of such information compounded distress for many older Australians.

- **Ensure that information is provided by a national, trusted source**. Use a consistent voice to present information and include advice on how to look after mental health and wellbeing. Information should encompass an awareness of the importance of social connections, which are crucial for good health and longevity.
- **Future messaging should include information about mental health and social connection**. During the Pandemic, the focus on physical wellbeing and impacts of COVID-19 disguised or minimised other impacts. Future messaging should move beyond hand hygiene to a focus on wellbeing and ensure that the message is 'Isolate physically not socially.'
- **Messaging should recognise that people's responses to the Pandemic and lockdowns are normal responses to extreme circumstances and are not pathological**. It should help older Australians identify that what they are experiencing is typical, not long-term and that there are ways to support and heal from these impacts. There should be a focus on messaging about living with the Pandemic.
- **Do not rely on exclusively digital means of communications**. Non-digital channels are especially important for older Australians who cannot or choose not to use the internet or find it increasingly challenging as they age. Many older people value and use traditional communication channels, such as printed newspapers, posters, senior specific publications, brochures, telephone, face to face, television and radio. This is particularly important for the distribution of information perceived by older people to be sensitive or personal.

3. Increase accessible mental health services and preventative measures that are informed by an understanding of ageism, ageing and gerontology

Social isolation and loneliness were the most frequently cited impacts of the Pandemic, and people identified that these led to worsening anxiety, mental ill health, fear and depression.

Adequate mental health support and services for Australians aged 75 and over require a focus on preventative measures along with acute treatments:

- Models that promote and normalise mental health services and language among young people could be used to encourage similar uptake among older people.
- Improved awareness necessitates provision of appropriate services. Any education and promotion around mental health and wellbeing should be accompanied by adequately funded and staffed services.
- Trauma-informed training for staff working with older Australians, at all levels, is crucial. The long-term impacts of the Pandemic are still unfolding. Services that provide support and mental health help need to understand the mental health impacts of ageing, trauma and ageism.

Our data supports national implementation of the recommendations of the Royal Commission into Victoria's Mental Health System, particularly those that relate to:

- The establishment of a responsive and integrated mental health and wellbeing service stream for Australians aged 75 and over, that focuses on improving their mental health and wellbeing outcomes and ensures that they have access to the same mental health treatment, care and support as the rest of the adult population.
- Provision of specialist mental health treatment, care and support for people with complex and compounding mental health needs generally related to ageing.

4. Target strategies at each level of government, including local government

Work with local government is essential. Local government responses need to be balanced with national oversight.

Explore how local government can facilitate service delivery for mental health and wellbeing and older people. Examine how this can be done alongside the local community. This may entail a risk register that manages the data for vulnerable populations:

- **Mental health emergency plans.** There needs to be a disaster management plan for older people with mental ill health. This could be a local government responsibility. Councils could develop individual plans with people and mental health providers to identify and plan for what they may need in times of crisis/disaster; and educate and equip people to know what they need, like the bushfire emergency plan.
- **Build capacity** for ordinary citizens to check in and strengthen connections and check-ups with neighbours and isolated older members of the community. This happened ad hoc during the Pandemic, but it should be systemic rather than a matter of luck. Find ways to encourage, facilitate and embed this long term.
- **Strengthen, fund and pilot place-based programs.** Identify models that work and translate them to mental health. Local governments are well placed to do this.
- Programs that receive government funding to provide services to older people need to develop their own plans to implement in times of disaster. This should be a condition of their funding.

5. Strengthen, fund and expand successful community engagement and ways of embedding community and social connections

The Pandemic Response Plan needs to champion community-based measures that facilitate and strengthen preventative and recovery measures. Community-based organisations that have extensive networks and the trust of marginalised communities should be funded to provide mental health outreach and education for priority groups, such as people from CALD communities. Mobilise community connections and invest in existing resources to reduce the burden on public health.

Locally tailored programs for mental health and wellbeing literacy

Locally tailored information and empowerment are vital. Older Australians need to be confident they can reach out to their respective communities for information.

- Tap into the rich seam of organisations that exist and can offer support – preventive and recovery. People and organisations want to help but don't know how.
- Identify community organisations as key conduits for social connections. Expand existing infrastructure and organisations.
- Provide targeted training and education to communities.

- Increase funding to the Community Visitors Scheme (CVS) beyond those receiving home care packages. The platform is in place and could be extended and provide support during times of national emergencies and crisis.
- Primary Health Networks (PHNs) and care finders are funded for assertive community engagement and outreach to understand the nuances of the populations they support. How could they be used better? Consider building on care finders or a similar model to support and reach older Australians, particularly those who may be marginalised.

6. Prioritise staff training and education in mental health awareness for people providing care and services to older people

A comprehensive Pandemic Response Plan must encompass strategies to support workers and carers during times of crisis. A skilled, professional workforce that delivers appropriate care must also receive the support to recover from any vicarious trauma.

The corollary to this is the provision of adequate training and understanding of ageism for people working with older Australians – to recognise that often, the mental health needs of older Australians are not an ‘normal’ part of ageing, but specific responses to the distress created by emergency situations such as Pandemics.

> *‘Even paradise is not paradise if you are lonely’*
>
> *Focus group participant*

Background

Why did we focus on Australians aged 75 and over?

Australians aged 75 and over are not a homogeneous group and faced diverse challenges through their lived experiences of the Pandemic.

This group were the segment of the population deemed most at risk of contracting and dying from COVID-19. Anecdotally, they are the group of older Australians most susceptible in times of crisis such as Pandemics, and likely to be experiencing a high incidence of frailty, disability and social isolation.

Despite this, a consistent body of research suggests that older Australians – often consolidated into a 65 years and over category – experience mental illness and distress at lower rates than other age groups,[6] and that this was also true during the Pandemic.[7] Such comparisons are limited in their relevance and efficacy and have serious implications for service provision and uptake. This group of older Australians faces specific, age-related challenges that increase exponentially with age, so that the differences in fragility, cognitive decline and disability may be more marked in someone who is 80 compared to a 65-year-old.

Our research focused on Australians aged 75 and over because we believe their experience and needs during times of national crisis are likely to be different to those of younger older Australians (65 to 74 years). The 'vulnerability' of this segment of older Australians is a function of biological ageing and ageism, which compound lifetime accumulated disadvantage (or, for some, advantages).

In Australia, over 70% of the people in residential care, home care and transition care were aged 80 and over on 30 June 2021.[8] People aged 75 and over also have an increased risk of developing and living with dementia. There are gendered differences among this cohort: as the population ages, there are more women,[9] and women have an increased risk of dementia, which is the leading cause of death for Australian women.[10] One in three older people is overseas born, and a significant proportion do not speak English as a first language, rendering them more likely to experience difficulties in accessing appropriate information and services.[11] This is a segment characterised by wide-ranging socio-economic differences, with a significant number who have lived their formative years in war or immediate post-war conditions.

Many have experienced the dislocation of migration, and of ageing and facing mortality in a 'foreign' country. There is also some evidence of an 'increase in racial microaggressions and xenophobia',[12] which has been borne by some communities and exacerbated a sense of fear and vulnerability among older members of these communities. Inclusive and equitable pandemic and other disaster responses must also address this.

What did we do?

- We conducted a national, online survey of people aged 75 and over, with 1,119 respondents. The survey was developed and tested with the advisory group. It was not a diagnostic tool but captured how older Australians understood their mental health and wellbeing during the Pandemic. (See Appendix 1.)
- We conducted semi-structured, in-depth interviews with 15 self-selected respondents aged between 75 and 93, with either lived experience of mental ill health, dementia, living in residential aged care, from CALD backgrounds or living in rural/ regional areas:
  - 4 with a pre-existing mental health condition (2 Greek speaking)
  - 3 living in residential aged care (Arabic speaking)
  - 3 Vietnamese speaking
  - 1 Cantonese speaking
  - 2 Mandarin speaking
  - 1 living in a rural area
  - 1 person living with dementia.
- We hosted five focus groups in collaboration with community organisations that have strong, pre-existing relationships with consumers, comprising:
  - CO.AS.IT., which provides services for Italian migrants to Australia and their descendants. 6 x Italian Speaking participants aged 82-95 years, accompanied by 6 regional managers of the CO.AS.IT visitation program.
  - Australian Greek Welfare (NSW, South Sydney branch) attended by 5 consumers aged 75 to 88, living in Southwest and Southeast Sydney.

  - The Multicultural Centre for Women's Health (MCWH), a Victorian-based health promotion organisation led by, for and with women from migrant and refugee backgrounds, was engaged to conduct focus groups with members of Melbourne's Chinese (7) and Vietnamese (5) communities. Instead of relying on translators, MCWH employs a team of bilingual and bicultural educators who have ongoing relationships with and are trusted by consumers.
  - The Coptic Orthodox Community group organised and co-facilitated a session with the CVS. The focus group was conducted face to face at St Mina Coptic Orthodox Church and was attended by 8 participants aged 75 to 94 and the group coordinator, who also participated in the focus group, having the requisite lived experience.
- We received 27 submissions through myPandemic.story@cota.org.au, a dedicated project website and inbox.
- We recruited and established a Project Advisory Panel, which met monthly and provided advice on all aspects of the project.
- We developed resources on simple strategies for better mental health and distributed these to older people through COTA Australia's member base.
- We conducted six half-hour interviews with consumers, advocates and workers to identify key issues, observations and areas for exploration and to inform initial project set-up.

Engagement strategy

The project aimed to capture the diversity of lived experience among people aged 75 and over, including those who, for various reasons, might not be accessed through an online survey, who do not speak or write in English or who may live in regional areas.

A key aim of this strategy was to build relationships with organisations that have networks and ongoing relationships with these communities for more sustained engagement. We identified groups who have strong and pre-existing relationships with diverse communities and reached out to engage their networks and expertise.[13]

Advisory Panel

The project was developed in collaboration with, and guided by, a Project Advisory Panel. Members were recruited through an Expression of Interest process promoted through COTA Australia's subscription and newsletter channels. All 16 respondents were interviewed and asked about their interest in engaging with the project, their lived experience of COVID-19 restrictions and impacts, their capacity to commit to ongoing engagement with the project, their ability to attend regular meetings, and willingness to provide feedback and guide the project.

Five people were selected, three within the target age group, and two representing organisations that provided services to consumers throughout the Pandemic and through periods of lockdown in various jurisdictions.[14] The Panel met online monthly for one hour. Members received weekly updates on the progress of the project and provided regular feedback and guidance.

Survey demographics

This section presents some key survey data to foreground the later qualitative and thematic analysis. It also compares the proportions of those who reported that their mental health was affected with those who reported it was not, over the first two years of the Pandemic.

Who did we reach with the survey?

The survey comprised 34 questions. It ran for four weeks from January to February 2022 and received 1,119 responses. The majority were completed online, five were completed over the telephone, and 10 were received via the post and entered manually.

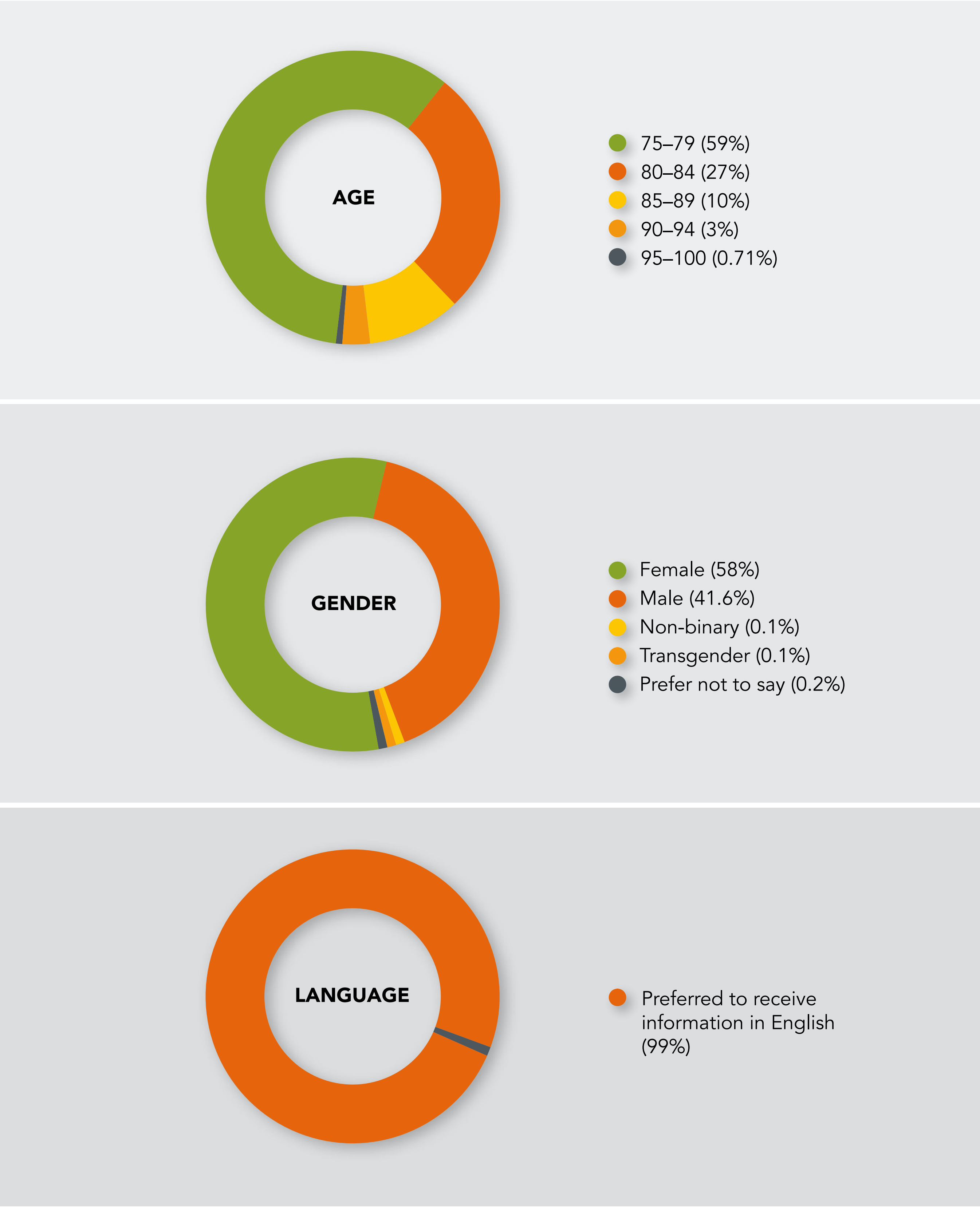
The online survey was promoted through COTA Australia's networks, COTA Australia's email lists and social media. The sample was self-selected, predominantly English-speaking, metropolitan based and with a digital presence and literacy.

The survey sample is not representative of the cultural and linguistic diversity of the broader Australian population. One in three Australians over the age of 65 are overseas born, 18% speak a language other than English at home, and among this cohort, English proficiency decreases with age.[15] To address this, we developed other strategies to access these communities, through language-specific focus groups and interviews with Greek, Italian, Cantonese, Mandarin, Vietnamese and Arabic speaking communities.

Appendix 2 details other groups of older Australians we did not reach with the survey, and who would require targeted engagement that was not possible within the constraints of this research, and the limitations of engagement due to COVID-19 fears.

Age, gender and preferred language of all survey respondents

Figure 1: Gender and age breakdown of survey respondents (n=1,119)



Where did they live?

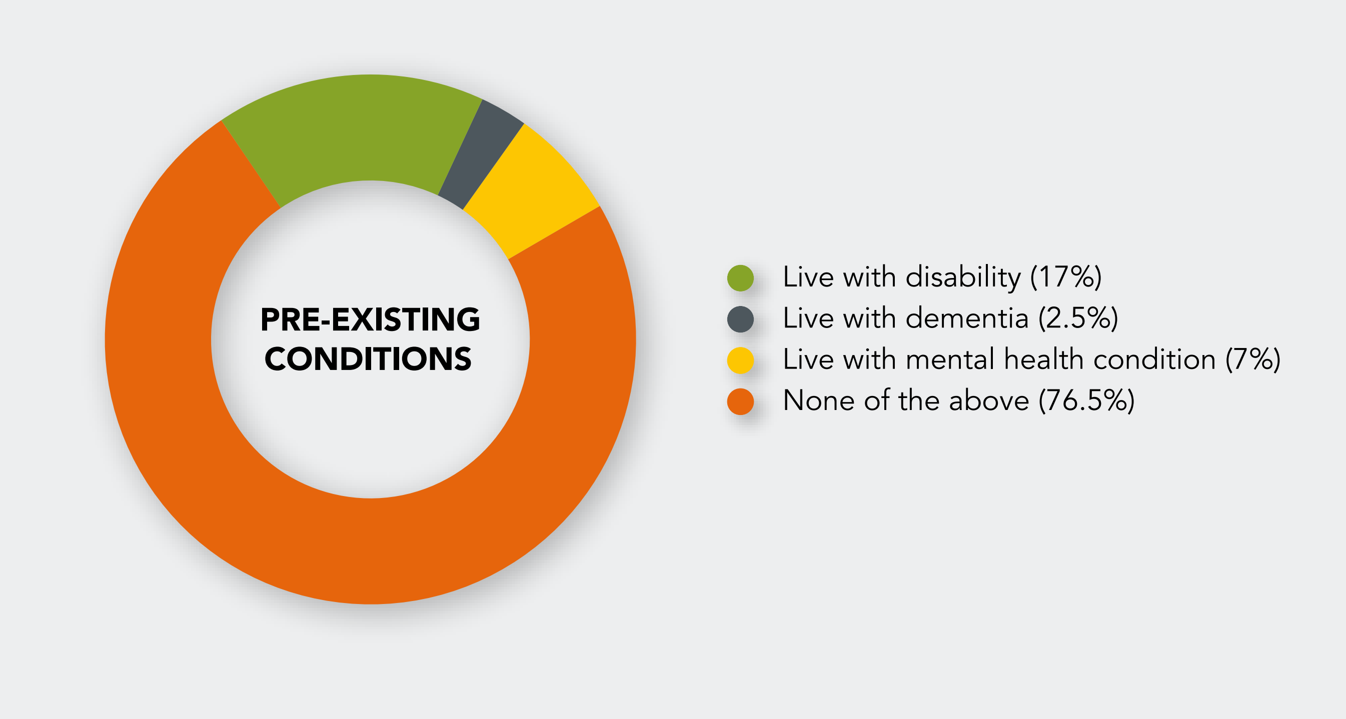
Over one third of our survey respondents were from NSW, followed by Victoria and South Australia. Most survey respondents (65%) lived in a capital or major city, with a further 21% in a regional city and 12% in rural areas.

Figure 2: Location of survey respondents (n=1,119)

Pre-existing health conditions

Most survey respondents did not identify as living with a disability, dementia, or mental health condition.

Figure 3: Pre-existing conditions of survey respondents (n=1,119)



While 17% indicated they lived with a disability, this is a much lower rate than the Australian Institute of Health and Welfare (AIHW) estimates, which indicate that 44% of people aged 65 and over live with disability and that this proportion increases with age.[16]

Receiving home care support or home care services: Most people who access aged care services receive them at home. A large proportion (62%) of respondents reported they did not receive home care or support services, but those that did were more likely to experience distress and detrimental impacts on their mental health during the Pandemic, particularly when services were cancelled or interrupted.

Informal carers: Nearly one third (30%) had informal caring responsibilities of a partner (20%), a child or grandchild (5%) or other (4%). Caring is also gendered, with 53% of carers being women, and 41% men. Women were also more likely to have caring responsibilities for a child or grandchild than were men and lived with a pre-existing mental health condition.

Life before the Pandemic: what we heard from survey respondents

While older age is often equated with loneliness and isolation,[17] this was not reflected in the survey data, with only 7% of respondents being lonely pre-Pandemic, 6% felt isolated and 3% reporting they were unhappy. Most (82%) had as much contact with friends as they wanted, and a large proportion (68%) were happy with their relationships and connections. They were active and participated in events and activities through local councils, faith groups and community groups.

Additionally (n=1,060):

- **60%** enjoyed regular physical activity
- **59%** knew their neighbours well enough to talk with regularly
- **56%** participated regularly in activities and events
- **36%** volunteered regularly.

However, only 23% agreed that even though they were not very social, that was acceptable to them. This suggested that social connections and activities may be more important than explicitly captured by the question. It is possible that the stigma associated with admitting or considering oneself lonely or isolated may have affected how people responded. By asking specific questions about different types of relationships and connections, we aimed to develop a more nuanced picture of the different types of loneliness, which can include social loneliness (the absence of larger social or community groups) and emotional loneliness (the absence or loss of close attachments).[18]

This is explored further in the thematic analysis, where the different experiences of isolation, loneliness and their impacts are discussed.

Key findings

These research findings provide an evidence base for the NMHC to monitor its progress against the National Mental Health and Wellbeing Pandemic Response Plan. The findings and recommendations were organised to support:

- New models to meet emerging needs.
- Facilitating access through coordination and integration.
- Identifying and addressing mental health risk factors and their social context.
- Identifying vulnerable populations and strategies to address their unique mental health and wellbeing needs and deliver tailored activities and resources to meet these needs.
- Suggestions for providing clear, consistent and appropriate communication.
- Suggestions to strengthen further iterations of the Plan by incorporating lessons learnt during the COVID-19 Pandemic on the most effective ways to gain lived experience insights.
- Suggestions for providing effective and appropriate support and response for current and ongoing needs.

1. Everyone was affected

The COVID-19 Pandemic and associated measures had profound impacts on the mental health and wellbeing of adults aged 75 and over.

The impacts of the Pandemic and lockdown measures on people aged 75 and over were profound, manifested in different ways (including loneliness, fear, worsening mental health and reduced physical activity, leading to cognitive decline) and were evident to varying degrees, even among those who said their mental health was 'not affected'.

The experience of lockdowns

Most respondents (97%) experienced at least one lockdown. During periods of lockdown, Australians aged 75 and over (n=1,004) reported that they:

- felt pessimistic about the future (21%)
- engaged less with friends (47%)
- stopped doing things [they] used to enjoy (40%)
- kept up social connections (33%)
- lost confidence (13%)
- found it difficult to sleep (15%).

Just over half (57%) reported that they ate well and had a good appetite, and 54% felt confident they could take care of themselves. While some respondents also reported positive experiences, these were not in the majority. During lockdowns, less than half (40%) felt well, and 39% felt that their routine did not change much. Only 20% enjoyed having more time to [themselves], and 18.5% reported that 'nothing changed, my life continued as before'. Instead, for most Australians aged 75 and over, the Pandemic wrought change and disturbance that affected their wellbeing.

While the majority reported that at least one person checked on them during periods of lockdown, usually a family member (70%), friend (37%) or neighbour (27%), nearly 13% did not have anyone check on them during these periods.

The worst impacts of lockdowns

When asked to identify the worst impacts of lockdowns, as many as applicable, the most frequently selected were disrupted social connections, decreased physical activity, feeling isolated, mood changes, worry and fear.

The most selected impact, chosen by 62% of respondents, was the inability to have friends and or family at home, followed by not being able to see friends or participate in social activities. Additionally:

- **42%** worried about getting COVID-19 or infecting others
- **41%** became less physically active
- **21%** felt isolated
- **19%** noticed mood changes.

Worst impacts of the Pandemic

Respondents were asked 'what have been the worst impacts of the COVID-19 Pandemic for you?' (n=1,015). They could choose as many options as were applicable to them. Most people identified isolation and loneliness, along with lost social connections, inability to mark important events such as funerals, family events and celebrations, and separation from family.

For 11%, the worst impact was the deterioration of their mental health.

Additionally:

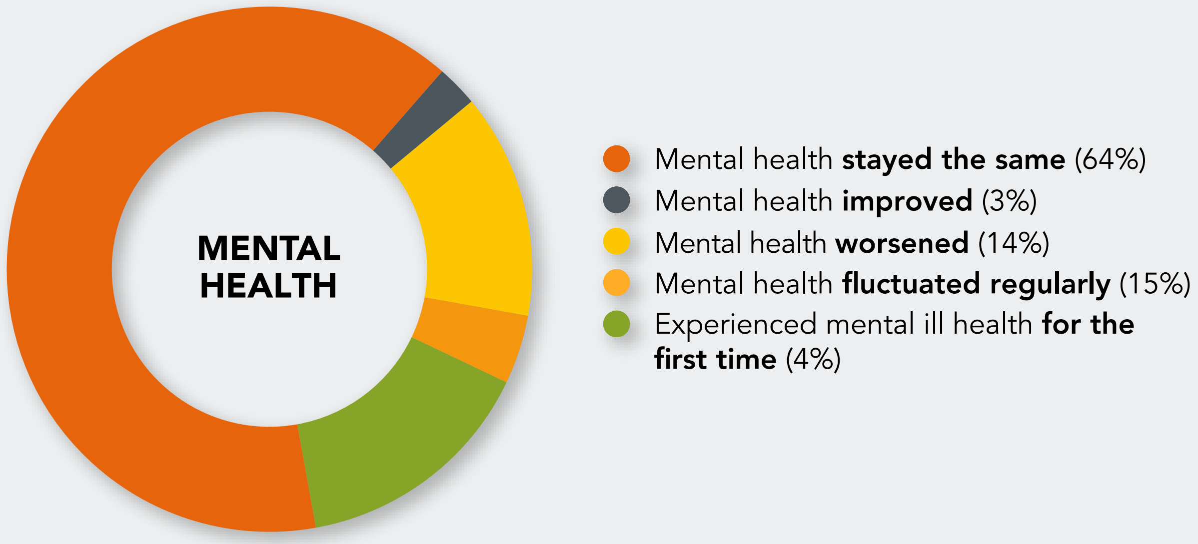
- **47%** felt they had missed out on important family events and celebrations (for example, arrival of grandchildren, significant birthdays)
- **37%** could not continue with their usual activities/volunteering
- **26%** missed the funerals of friends and family that passed away
- **24%** experienced isolation
- **18%** experienced loneliness
- **15%** felt they had lost their social connections
- **11%** were living with fear

One quarter (25%) of respondents agreed that the Pandemic will have long-term impacts on their mental health, and 10% strongly agreed.

Despite the prevalence and duration of these impacts, 64% of total respondents (n=1,060) reported that their mental health stayed the same over the last two years (February 2020 to February 2022), a period covering the beginning of Pandemic measures and lockdowns.

During this period, 4% of reported that they experienced mental ill health for the first time in their lives; for 14% it worsened, for 15% it fluctuated and 3% reported an improvement.

Figure 4: Self-reported mental health status of all respondents over first two years of the Pandemic (n=1,060)



The impacts of the Pandemic were not experienced equally. Of those who reported that their mental health had worsened:

66%	were women
33%	had caring responsibilities
6%	were living with dementia, compared with less than 1% of those who were unaffected
28%	lived with disability
39%	had experienced a mental illness or lived with periods of sadness and depression before the Pandemic
6%	were living in residential aged care, compared with less than 0.05% of those whose mental health was unaffected
56%	were receiving home care support and services.

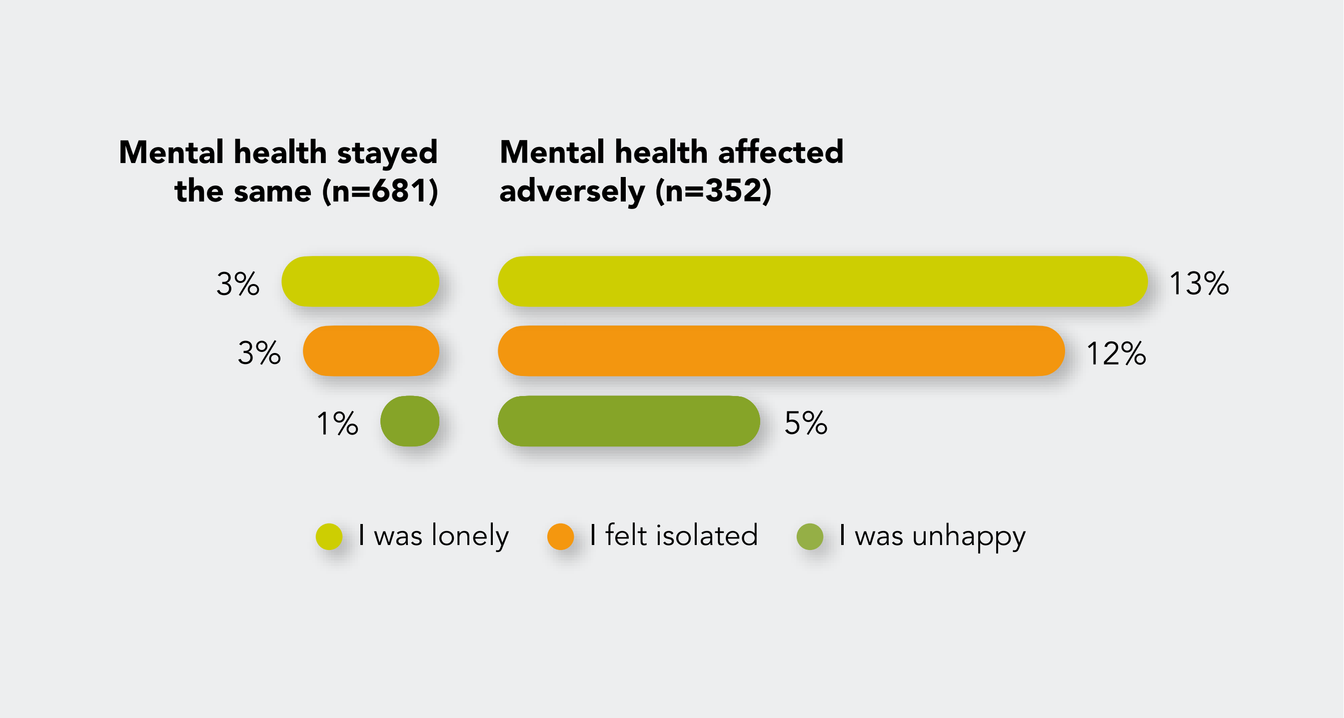
Key differences between those who reported being affected and those who did not

The following section discusses the key differences between the two groups – those who reporting being affected by the Pandemic and those who reported they were not – as indicated in their responses to both the quantitative and open-ended qualitative questions in the survey.

Pre-Pandemic life

People who felt that their mental health was adversely affected by the Pandemic reported higher levels of loneliness, unhappiness, and isolation pre-Pandemic compared to those who felt unaffected by the Pandemic.

Figure 5: Isolation, loneliness and unhappiness before the Pandemic – comparison between those whose mental health stayed the same and those who reported adverse effects

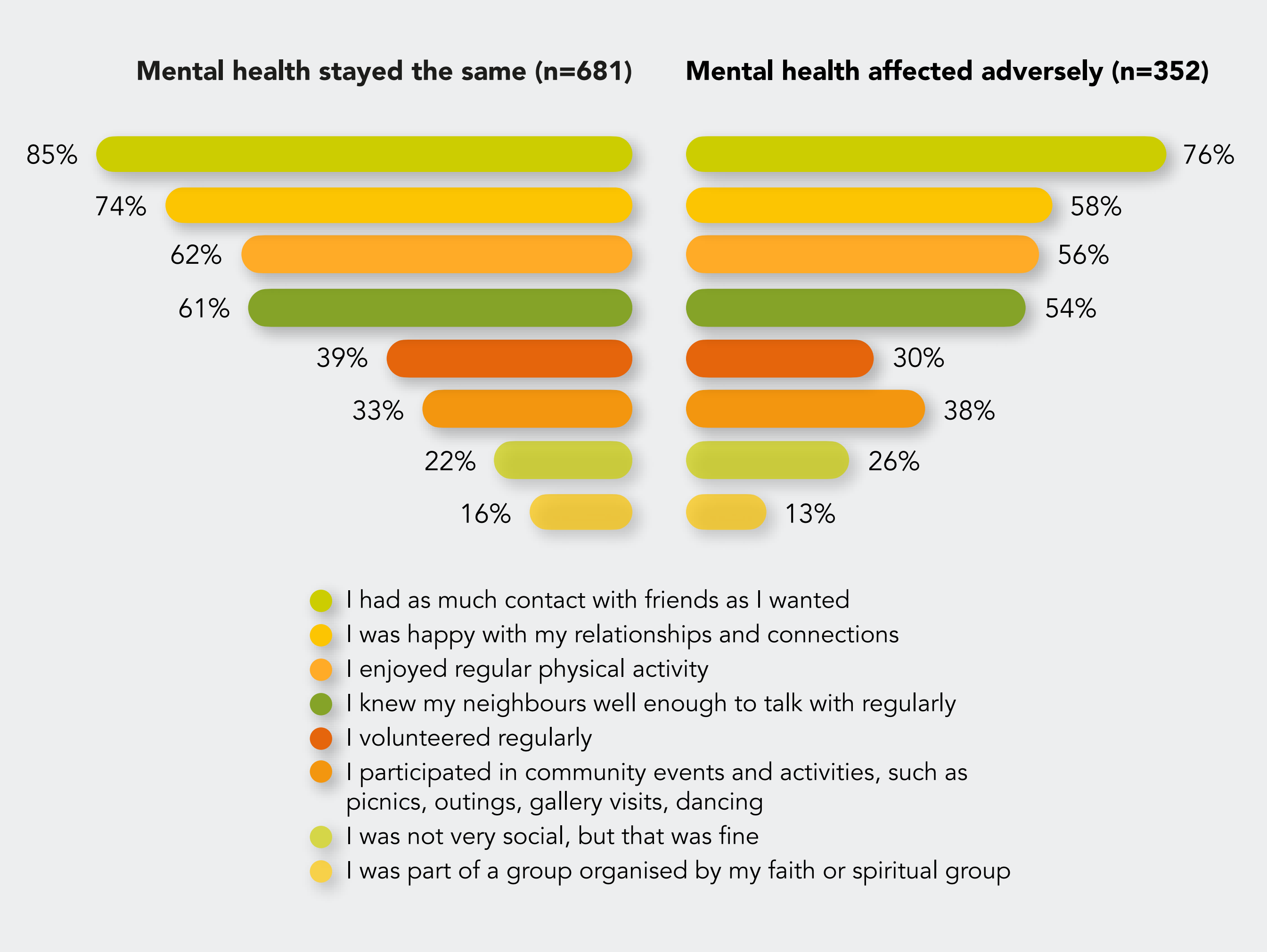


Older Australians who identified as being adversely affected also reported less satisfaction with their relationships and social connections, were less physically active, not very social but less likely to be comfortable with it and had slightly higher engagement with activities run by community groups and local councils, as detailed in Figure 6.

Of those who reported adverse impacts on their mental health (n=352):

- **63%** had a pre-existing mental health condition
- **42%** reported their mental health worsened during the Pandemic
- **68%** agreed/strongly agreed that the Pandemic will have long-term effects on their mental health
- **89%** did not use mental health services
- **8%** thought about suicide during periods of lockdown.

Figure 6: Life before the Pandemic – comparison between those whose mental health stayed the same and those who reported adverse effects



Experiences of lockdown

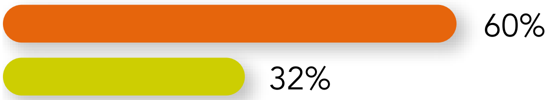
There are clear differences in how the two groups experienced the impacts of the Pandemic. While a significant proportion of both groups chose not being able to 'receive friends, family at home' as the worst impact (62%), there were differences in how they reported other impacts.

Of those whose mental health was affected during the Pandemic:

Decline in social activities

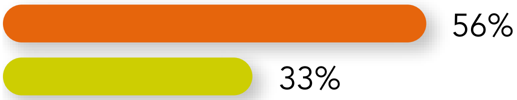
63% reported being affected by not being able to participate in social activities, compared to **55%** of those who reported that their mental health stayed the same.

Decline in physical activities



60% became less physically active compared to **32%** of those who reported that their mental health stayed the same.

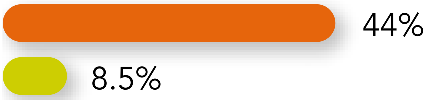
Worried about COVID 19 infection



56% worried about getting COVID-19 or infecting someone, compared to **33%** of those who reported that their mental health stayed the same.

There are also stark differences between the two groups in relation to isolation, mood and the experience and impacts of lockdowns:

Isolation

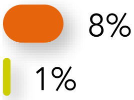


44% felt isolated compared to **8.5%** of those who did not consider their mental health affected.

Mood changes

47% noticed changes in their mood compared to **4%** of those who did not consider their mental health affected.

Felt suicidal



8% felt suicidal compared to **1%** of those who did not consider their mental health affected.

Lost sense of purpose

28% lost sense of purpose, compared to **3%** of those who did not consider their mental health affected.

During period of lockdowns

Additionally, during periods of lockdown, people whose mental health was adversely affected reported that:

- **40%** stopped doing things they enjoyed
- **22%** became pessimistic about the future
- **47%** engaged less with friends.

In comparison, of those who said that their mental health was unaffected:

- **30%** stopped doings things they enjoyed
- **10%** became pessimistic about the future
- **38%** engaged less with friends.

Both groups reported experiencing isolation, decreased physical activity and loss of sense of purpose, but those who considered themselves unaffected also reported feeling well (55%), and feeling confident they could look after themselves (66%). All groups were affected by separation from family and friends and missing out on important family events.

Those who identified as having a pre-existing mental health condition were the most affected, as were people living in residential aged care, those with caring responsibilities and those living with disability. Figure 7 provides a detailed breakdown of how older Australians experienced lockdowns.

The biggest differences between the two groups were in the reported rates of isolation, loneliness and fear, as demonstrated in Figure 8.

Figure 7: Experiences of lockdowns – comparison between those whose mental health stayed the same and those who reported adverse effects

During periods of lockdown:

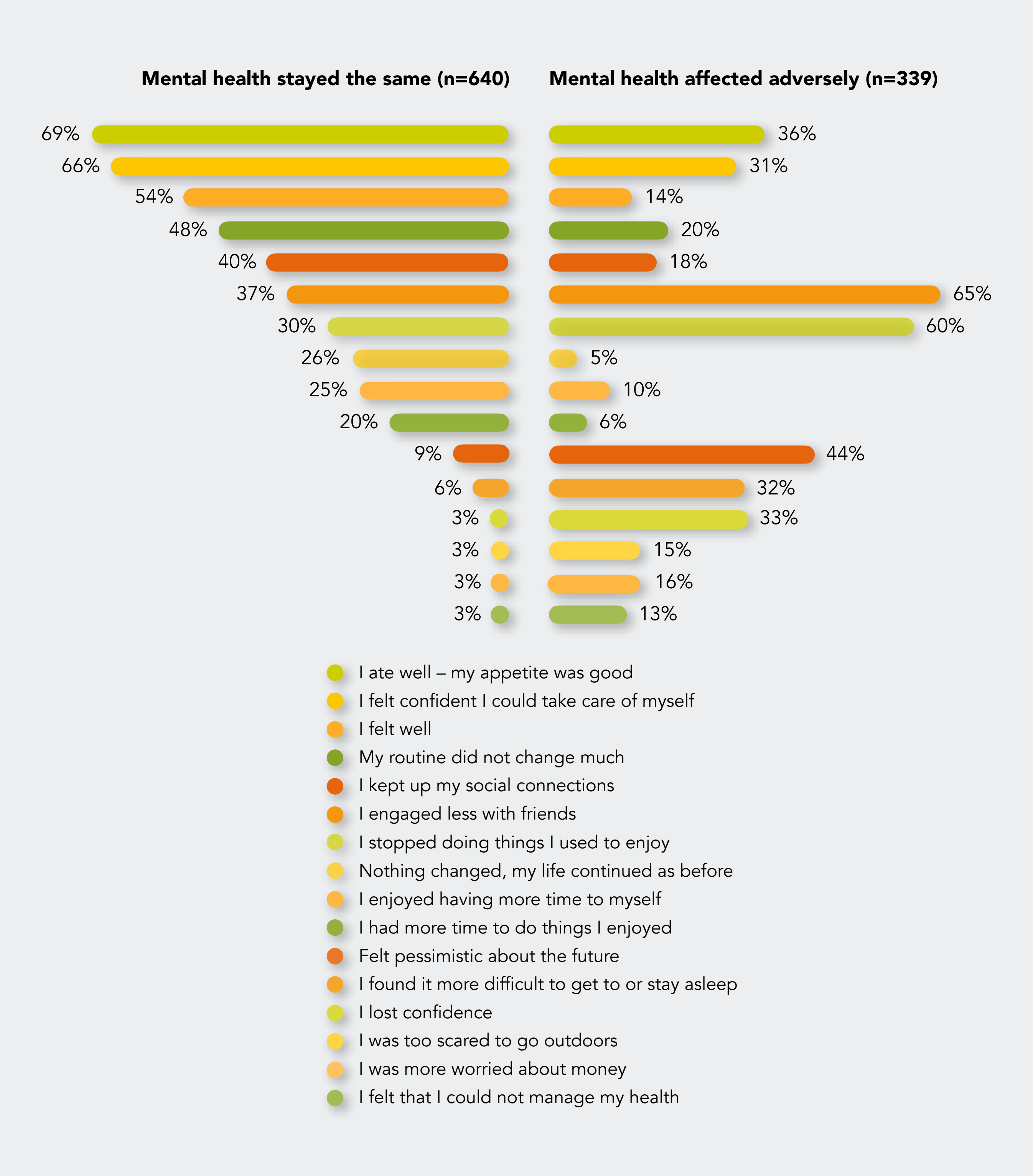
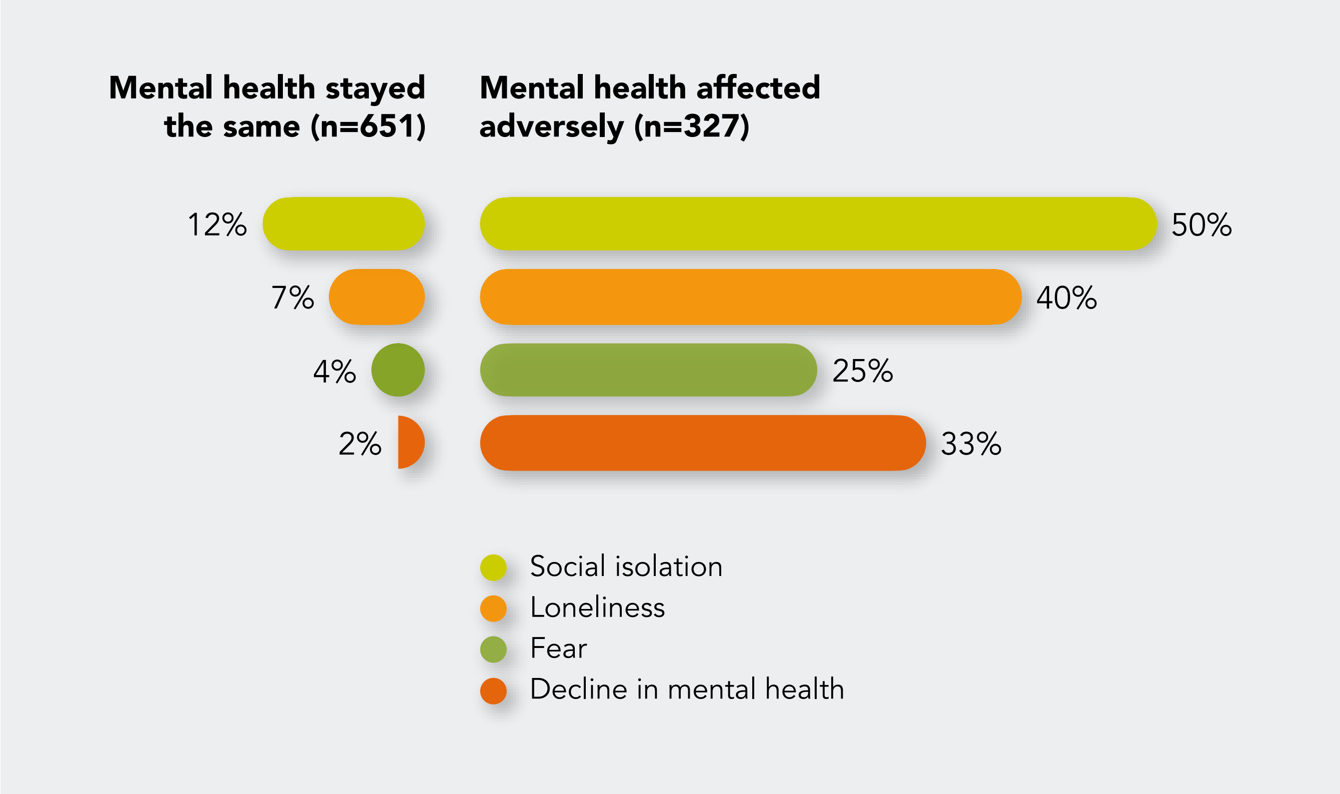


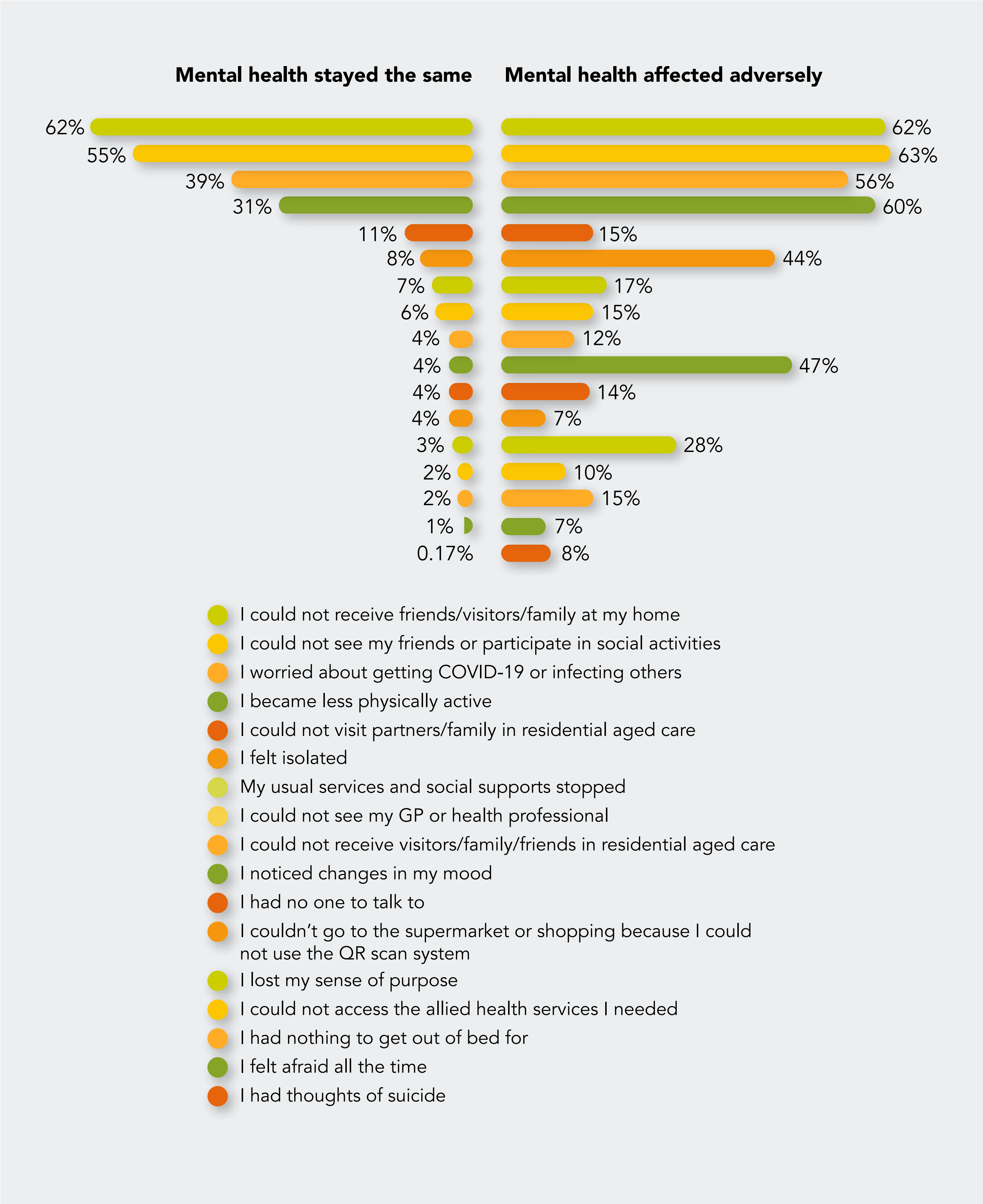
Figure 8: Social isolation, loneliness, fear and decline in mental health during lockdowns – comparison between those whose mental health stayed the same and those who reported adverse effects



Worst impacts of lockdowns

When asked to select all the options that described the worst impacts of lockdowns, respondents in both groups consistently identified the same top five but these were not experienced at the same rate. All respondents identified disruption to family connections and social activities as the worst impacts. However, those with reported mental distress during the Pandemic also reported decreased physical activity, feelings of isolation, mood changes and feelings of suicide at far higher rates, as shown in Figure 9.

Figure 9: The worst impacts of lockdowns – comparison between those whose mental health stayed the same and those who reported adverse effects (n=978)



Fear and increased awareness of vulnerability

Of the older Australians who considered themselves affected by the Pandemic, 7% reported that they 'felt afraid all the time' during periods of lockdown. They also 'worried more about getting COVID-19 or infecting others'. In comparison, the survey data tells us that less than 1% of the people whose mental health stayed the same reported feeling fear as an impact of lockdowns.

This fear and its ongoing impacts were also strong themes in focus groups and submissions:

> *I am not the same as I was before COVID lockdown, I live in fear. I don't leave the house anymore. (Focus group participant)*

> *Still now I want to stay home, now I am scared, maybe someone has the disease. It's a gamble to leave the house. (Focus group participant)*

> *I was scared, so scared all the time. I could catch it everywhere. Today is the first day I have left the house, to come here. (Focus group participant)*

> *Fearful of needing hospital treatment and knowing I won't get help in the way it was before COVID. More fearful, nervy. Lost friends and suspicious of where they have been and what they have done in relation to catching or being a carrier of COVID-19. Family nervous about visiting us or having us visit them. Fearful of health outcome as hospitals understaffed and competent medical staff have left. Depressed. Just managing with painting and planting vegetables. (Submission)*

Impacts of disrupted social connections

Loneliness and isolation

For people aged 75 and over who participated in the survey, the most frequently identified impacts of the Pandemic were increased loneliness, isolation, anxiety, and living with fear. Over half of survey respondents cited 'separation from family' as the worst impact of the Pandemic. Qualitative data through focus groups, interviews and submissions presents a detailed, nuanced picture of this finding. The distress caused by social isolation and separation from family and friends is a powerful, recurring theme across all data sources:

> *Arguing with husband. Resignation from clubs and lunches. Lonely. (Submission)*

> *I'm very sad. I haven't been the same since before COVID-19. Crying, praying a lot. I'm sad on my own. (Focus group participant)*

We heard from people who were struggling with loneliness and social isolation that:

> *I wish I had one other person in the house. (Survey respondent)*

What mattered was not the number of connections, but that those that were available were enough to meet people's needs.

For 48% of respondents overall, this was the worst impact of the Pandemic:

> *I live alone, and I knew it was important to have voices in the background, so I watched footy, racing, interesting conversations, so I could have interactions and backchat to umpires. It helped augment my speech. One of my friends, in her 90s, had so little contact she lost her speech. She is certainly now frailer, older, her cognition has deteriorated. She has had to have speech therapy.*
>
> *She declined because she did not speak. We thought it was dementia, but it was just lack of speaking. (Interviewee)*

In focus groups, people spoke of the loss of social connections and activities, and their 'brutal' impacts:

> *I stayed in my little flat. I live alone. I missed dancing, so I would put music on and dance a little bit with my broom. I was lonely. I cried every day, just cried and then felt better. I could not believe this was happening to me. It was too much. No kiss, no cuddles for six months. Brutal. (Focus group participant)*

Those who have identified that the Pandemic has affected their mental health have expressed feelings of loneliness, worry about connecting with people, worry about the future, and further deterioration of pre-existing mental health concerns. For some, these impacts are ongoing:

> *I stay indoors except for church and visit the cemetery. Not comfortable to go out. (Focus group participant)*

> *Today is my first outing and I feel very nervous. (Focus group participant)*

Many were distressed by missing out on important family events and celebrations (for example, arrival of grandchildren, significant birthdays):

> *Unable to mix and see old friends and family. Unable to holiday when and where we want to. Fear of contacting COVID-19 due to underlying health problems. The distress of knowing family members have contracted the Pandemic: my daughter and son in law in Queensland and my sister and niece in Sydney – unable to visit. Unable to entertain at home. Missed family Christmas, fear of attending. Missed birthdays and other celebrations. (Submission)*

In submissions, older Australians wrote in detail of the impacts of isolation, and the resultant loss of social skills and joy:

> *Because of all the restrictions in socialising, I am now in the habit of not socialising – to my detriment. I doubt if my pre-COVID joie de vivre will ever return. (Submission)*

> *I've lost social skills through having been at home so much and not interacting with people face to face. (Submission)*

And for some, the impacts were not immediately obvious:

Early in January 2022, I was at a hotel buying drinks for four of us when a man came and stood right beside me to order his drink; both of us were unmasked. He started to reach over me to pay for his drink and I objected. Then the serving person called him to my other side, and he was paying for his drink standing right beside me.

(continued)

By this stage I was furious with him, and his only response was 'I'm not touching you'. He had no idea of social distancing. Luckily, he moved away quickly, and I was able to cool down, but my strong reaction surprised me and caused much soul-searching and though I had felt no problems with COVID yet, somewhere deep down there was much anxiety.

It took me a couple of weeks to process this and now I am more aware that sometimes one needs to dig a little deeper when one thinks all is OK! (Submission)

Physical decline and mental and cognitive decline

For 35% of respondents, the worst impact of the Pandemic and lockdown measures was becoming less physically active, which for many also brought about a decline in motivation and wellbeing:

> *Exercise was stopped during lockdowns which affected my mobility and wellbeing. Telehealth calls a waste of time; they can't see how we are! And don't understand brain fog at all. (Survey respondent)*

> *Walking my friend's dog gave me an opportunity to speak with people. This was my most important part of my weekdays. On weekends I would do nothing and hardly get out of bed…just a general feeling of depression. (Survey respondent)*

> *My body hurts and this affects my mental health. All appointments have been put on hold in the public hospital system. Referral to rheumatologist suspended. Orthopaedic appointment at least a year away. Enough to make anyone depressed! (Survey respondent)*

Physical activity in older people is crucial to reduce the risks of falls, 'fractures, limitations in activities of daily living (ADLs), functional limitations, cognitive decline, and depression.'[19] Many people were experiencing depression bought about by the loss of mobility and independence that, in turn, was a result of reduced physical activity and exercise. One regional health administrator reported that:[20]

My team and I have supported older people in the community during COVID-19 lockdowns. We watched people deteriorate mentally and physically from staying in their homes for long periods and walking not much further than the bedroom to the lounge. (Interviewee)

For some survey respondents, an inability, or the fear of not being able to 'look after myself', was an impact of the Pandemic:

> *Mentally, I feel fine. Physically, I can now only walk 2 km a day. I still drive. I can order online from the supermarket. And we have good local shops. All in all, I think I am lucky. But in another pandemic crisis, I think I would feel very frustrated if it meant I couldn't look after myself. (Survey respondent)*

Bereavement and grief

Bereavement and grief, exacerbated by the inability to mourn and say goodbye, affected the wellbeing of many older Australians, with 25% of respondents overall citing this as a key impact of the Pandemic, and 25% of people aged 85-89 rating this as the top impact.

One respondent asked for:

> *More empathy to be shown for those with loved ones in nursing homes or facing death. I feel there will be long-term repercussions for those unable to grieve the loss of loved ones. (Survey respondent)*

Others articulated the consequences of Pandemic health measures on their wellbeing:

> *The impact on my mental health was due to the fact that the hospital refused to let me be with my husband when he died because he had been tested for COVID-19. This was despite the fact that I had been with him earlier that day. He was negative but I had to ring up for the results. Number restrictions at his funeral compounded the issue. (Survey respondent)*

> *I will feel better after COVID-19 and grieving the loss of my husband. (Survey respondent)*

For 25% of people aged 85-89, being unable to attend funerals and say goodbye to loved ones was among the top five impacts of the Pandemic. Increased loss, interruption to mourning and support services, combined with lockdown restrictions and isolation, placed a devastating burden on people's wellbeing:

> *I could not comfort or touch my dying sister who lived interstate. I could not attend my sister's funeral, to experience some sense of closure. (Submission)*

> *I am coming to terms with the death of two friends and unexpected transfer of others to aged care residential accommodation. (Submission)*

Others asked for:

> *Better access to loved ones in care and to be there when they are dying. Human touch by family is so important. (Survey respondent)*

My Pandemic Story

The Pandemic has affected all of us in some way, whether in a small way or with greater impact. It has caused much suffering, grief and death and probably has been the most impactful event since the Second World War.

For me, it caused my husband's early death at 77. I had been forced to put him into care 18 months before he died. COVID-19 ravaged the aged care home he was living in. The staff were kind and caring but infection control was not as good as it could have been. Like other homes, visiting access was restricted and stopped from time to time, yet it was the staff ultimately who brought in the disease. I could not see him for nine weeks prior to his death.

It was the most awful time of my life and our family's life, so it certainly affected our mental health. Personally, I coped because of my contact with my two daughters and other family and friends. This was by phone calls, Zoom and Skype. Even in severe lockdown, I could walk with a friend. Doing things for others, always helps the 'giver' as well. It could be checking on an elderly or unwell relative or friend or sending a small gift or some food.

(Submission)

Both groups reported that they stopped 'doing things I enjoyed' and became pessimistic about the future and engaged less with friends. While both groups also reported feeling isolated and experienced decreased physical activity and loss of sense of purpose, those who considered themselves unaffected also reported feeling well (55%) and feeling confident they could look after themselves (66%). Loss of confidence, and loss of appetite and sleep, were reported at higher rates by those who stated that their mental health fluctuated or worsened during the Pandemic:

> *[The Pandemic] exacerbated pre-COVID difficulties: my personal situation has changed very significantly before the Pandemic, due to my husband's stroke in September 2019 and consequent expressive aphasia which caused a marked deterioration of our ability to engage socially, his support group was also cancelled which added to our stressful situation. (Submission)*

> *Now I have nobody but my wife that knows or remembers the world as I knew it. I feel like an alien. (Survey respondent)*

> *If it wasn't for my cat to care for, and it snuggling up to me, life would have been more difficult, not being able to see my family. (Submission)*

One woman whose mental health had 'fluctuated regularly' during the Pandemic responded that:

> *I felt flat and unmotivated to seek help, although I'm quite capable of doing so. Most of my friends feel the same way. My interest groups have all cancelled meetings because members are afraid of catching COVID. I'm a retired teacher and normally actively involved in the education of my pre-school grandchildren. I used to organise craft activities and spend time with them every Tuesday, but COVID put a stop to that. I used to feel that I had something to contribute, but since COVID, despite not having lost my skills and abilities, my feelings of irrelevance have been exacerbated. (Survey respondent)*

Others reported experiencing 'some depression caused by isolation from family and friends,' and increased anger and rage:

> *I spent a night in hospital with breathlessness and palpitations. Anxiety. (Survey respondent)*

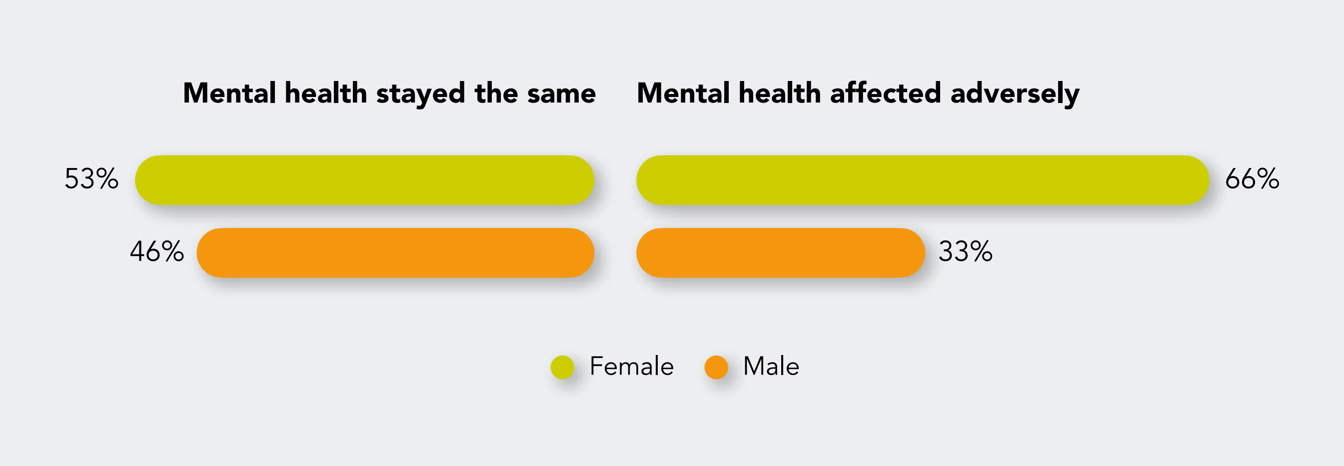
> *Oh, I could tell you all about these stupid, stupid restrictions and lockdowns. Don't get me started, I just get so angry, full of rage. I cope with the anger by going into my garden and pulling out weeds. My garden saved me. (Survey respondent)*

Particularly affected older Australians

Women

There were gendered differences in the results, with 66% of those who reported that their mental health was affected being women (Figure 10).

Figure 10: Gender differences – comparison between those whose mental health stayed the same and those who reported adverse effects (n=1,056)



A significant proportion of women in our research lived independently in their own home (40%) and reported feeling isolated, lonely and suffering from separation from family and friends.

When asked what would help, responses included staying connected to friends, family and community groups, regular exercise, and to a lesser extent, telehealth services:

> *Access to telephone mental health practitioners. (Survey respondent)*

> *What would be ideal would be to have home visitors check in weekly on elderly people living in their own homes. (Survey respondent)*

These findings may indicate higher and sustained impacts on women's mental health and necessitate that any gender-sensitive approach in the National Pandemic Mental Health Response Plan addresses the needs of older women and ensures that women aged 75 and over receive targeted mental health and other support.

This survey did not ask questions about family violence and elder abuse, so we have no quantitative data to measure this. However, increased violence was suggested obliquely in focus groups, where some women spoke of the 'tension and stress and fighting between couples' during lockdowns, and increased anger experienced by their adult children:

> *My son gets angry when I keep asking him to explain or translate what the government is saying. Questions, questions, questions, he keeps shouting. Why do you keep asking? But I need to know. (Focus group participant)*

> *It is difficult to know who to trust. Heated arguments in family, not sure if you're getting the right information. (Focus group participant)*

Australian research suggests that rates of clinically significant symptoms of depression and anxiety during the Pandemic were higher among women than men, and that this may in part be explained by their disproportionate burden of unpaid caregiving.[21] This is consistent with research that suggests women's experience of increased anxiety during lockdowns may be exacerbated by caring responsibilities or abuse.[22]

> *And another thing like… domestic violence is caused by mental health. It was not just between husband and wife but also between a child and his/her mum/dad. And the government did not have enough staff [during the Pandemic] to help those people. (Focus group participant)*

A report by Gender Equity Victoria on the mental health impacts of the Pandemic on migrant and refugee women calls for 'development and delivery of COVID-19 recovery mental health programs that are specifically tailored for migrant and refugee women' but did not include women over 75 in the research.[23]

Age, and recognising the systemic barriers created by gendered ageism, must also inform intersectional approaches to mental health service delivery.

People with pre-existing mental health conditions

> *I wake up every day stressed. I took up drinking a lot more than I normally would, because of the stress. I have post-traumatic stress disorder, so this (social isolation) really stresses me out a lot. (Interviewee)*

Older Australians who identified as having pre-existing mental health conditions (33%) were more likely to report being adversely affected by the Pandemic when compared to those who did not report having experiencing periods of depression or mental illness. While 37% reported their mental health stayed the same, 27% reported that it worsened, and 27% that it fluctuated regularly. A small percentage (4%) reported an improvement.

Of those who reached out for support, most received help from a General Practitioner (GP), family/friends or a counsellor or took medication. While 11% reported using telehealth during the Pandemic to speak with a psychiatrist, psychologist or counsellor, this was not a successful option for many, and telehealth was not a preferred option for most:

> *I had one telehealth consultation (early April 2020) with my psychiatrist, and I was not very pleased with this method of consultation. I have not revisited my psychiatrist since this telehealth despite my wife trying to encourage me to do so. (Interviewee)*

Instead, consulting GPs and maintaining connections with family and friends were the preferred options for staying well, with 35% reporting 'my GP offers enough support', and 16% 'because the formal mental health system does not understand the needs of older people'. This group was also critical of the use of mental health services ('they are not useful' and 'good therapists are rare'), and noted long waiting times for appointments, the high cost of treatment and a preference for face-to-face appointments rather than telehealth. The difficulties of getting appointments were raised repeatedly, ranging from mobility issues, the cessation of transport services by providers and other lockdown impositions:

> *I was unable to visit my psychologist due to lockdown. I was told that I have to do a face-to-face visit before I can get Zoom contact visits. (Interviewee)*

> *I've been suffering from acute depression for many years prior to COVID, so all the Pandemic did was to exacerbate my problems. Providing more social interaction would be helpful but is precluded because it IS a Pandemic. (Survey respondent)*

This cohort also considered that their mental health and wellbeing would be affected long-term by the Pandemic and lockdown measures: 48% agreed, and 20% strongly agreed.

> *Peoples' mental health has declined because of it. It doesn't help your mental health because you are living on high alert all day very day, because you don't know when the next thing is going to hit you. It is high flight or fright, hypervigilant mode. And if you have PTSD, it is worse still…they have said that people have taken up more drinking, and it is true. I am drinking more. It is strange because I don't even drink when I go out, but now at home I have to force myself to have a few days without drink. It is not a good thing. (Interviewee)*

People living with disability

Nearly one quarter of people living with disability reported they experienced a deterioration in their mental health during the Pandemic. Reasons included isolation and loneliness, disruption to social relationships and reduced access to services:

> *All face-to-face services were suspended. I could have received advice over the phone but as I moved during the Pandemic to be closer to family, I was not able to receive support for myself and my Guide Dog to orientate and negotiate my new environment and its surroundings. (Survey respondent)*

The prevalence of disability increases with age; AIHW data indicates that 50% of people aged 65 and over have disability. Further analysis shows that 44% of people with disability in Australia are aged 65 and over.[24] In the survey sample, 17% reported they lived with disability, and 11% reported they also live with a mental health illness. A large proportion of those aged 75 and over living with disability also received home care packages and support.

Of those older Australians living with disability, 35% agreed with the statement that the Pandemic will continue to have long-term impacts on their mental health and wellbeing, with 17.5% strongly agreeing.

One woman, aged between 80 and 84, who identified as living with a disability, reported that during the Pandemic, she experienced mental ill health for the first time, and believed that these impacts will be long term:

> *My only surviving relative lives in NZ. We talk regularly by phone. I HATE technology and my doctor laughingly called it 'situational panic attack' but no help was offered. I live in a retirement village with no amenities, and we are regularly told that we are 'independent' and need to look after ourselves. They had out RUOK postcards so that WE can send them to other people. I have had no phone call from management inquiring about my 'health'. Information is general and printed directly off the NSW Health website, nothing is edited to be appropriate to my village. (Survey respondent living with disability)*

The reliance on technology posed limitations, and for some created stress and anxiety:

> *I developed anxiety around using technology and felt intimidated and forced into engagement and felt foolish when I had to admit to difficulties with chronic fatigue syndrome. Regularly told to 'get your son/daughter/grandchild to help'. What happens when you don't have one of these to call upon? 'I'm alright Jack' was the attitude of most of my acquaintances. (Survey respondent living with disability)*

> *Life is centred around being able to use modern technology which a lot of older people can't manage or don't have. I can just manage but if something went wrong with my phone or iPad I would be lost. Being able to talk to my GP on the phone has been a great help – being in a wheelchair and not able to drive. (Submission)*

People in residential aged care

A particularly vulnerable group were people in residential aged care who, while comprising 2.5% of survey respondents, were disproportionately affected by lockdowns, restrictions to visitors and impacts of COVID-19 infection. In total, thirty-two (32) survey respondents identified as living in a residential aged care. Of these, 44% identified as living with dementia and 34% as living with a disability. The majority (23) are female, with the following age breakdown:

- 12 aged between 75 and 79
- 7 aged between 80 and 84
- 5 aged between 85 and 89
- 5 aged between 90 and 94 and
- 3 between 95 and 99.

One quarter (25%) live with a mental health condition. Prior to the Pandemic and lockdowns, 48% reported receiving treatment or support for a mental health condition and 33% reported living with sadness and depression, but also long periods of wellness.

Of those who had received support for a mental health condition before the Pandemic, the majority relied on a GP or medication, or a combination of both. Two respondents had also consulted a specialist geriatrician, and four had seen a psychologist. None of the respondents in residential aged care referred to receiving treatment from a psychiatrist or psychiatric nurse or dementia specialist at any stage.

Prior to the Pandemic and lockdown measures, respondents in a nursing home described themselves as 'having as much contact with friends as they wanted' (77%), 'participating in events and activities' (33%), 'enjoying regular physical activity' (37%), and 'happy with my relationships and connections (55%). Some also reported unhappiness (15%), loneliness (15%) and feeling isolated (7%).

Older Australians in residential aged care responded that over the course of the Pandemic, their mental health worsened (41%) or fluctuated regularly (26%) and 11% reported that they experienced mental ill health for the first time in their lives. One person (4%) reported that their mental health improved during this period, and for 18.5%, it stayed the same. For many, this was connected to the number and severity of lockdowns:

> *Being in a nursing home and being locked up for months was devasting. For anyone to think it was acceptable to lock people up, to deny them any visits, to bar them from stepping out, was inhumane. And all so the government could claim low death figures. A despicable act. My wife took me out of the nursing home. (Survey respondent)*

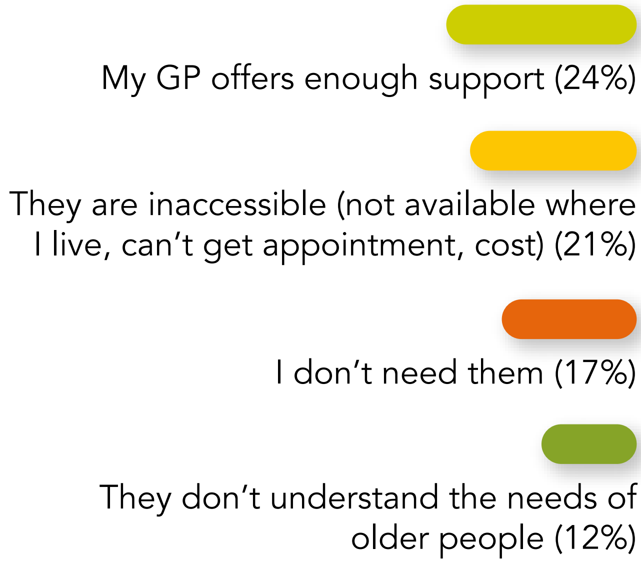
While those who had access to an iPad or mobile phones kept in contact with their families, this did not assuage the distress and loneliness:

> *I found it difficult when the nursing home had to go into lockdown. I am dependent on my daughter, especially for emotional support. We were able to have window visits and video calls, but I still struggled. (Survey respondent)*

For many, these impacts will continue beyond the lockdowns: 41% strongly agreed with the statement that ‘the COVID-19 Pandemic will continue to have long-term impacts on my mental health and wellbeing’ and 37% agreed.

> *My family have been denied access to me. I am completely dependent and cannot do much at all for myself. I had a very serious stroke in Feb 2020 at the start of the Pandemic and could not return to my home and independent living. My family, despite having so limited access to me, have had to sell my home and organise my life while I vegetate. Nobody in this residential centre is prepared to offer any real compassionate help for anything. I am just a burden on their daily task list. (Survey respondent)*

Despite this, only two respondents in residential aged care reported that they were currently using services such as those provided by a psychologist, community mental health, psychiatrists or other mental health professionals. The top reasons for not using these services include:



> *I have a GP who attends the nursing home. My medications keep me relatively stable. (Survey respondent)*

Some cited the difficulties of getting such assistance in a nursing home, particularly during lockdowns:

> *The aged care centre will do nothing for me unless my family call by phone or email and make a huge fuss. How would I access mental health support when I cannot even get help to go to the toilet? (Survey respondent)*

> *We are in lockdown for weeks on end, confined to our rooms. (Survey respondent)*

The enforced separation from family and not being able to receive visitors had harmful impacts on the mental health of many respondents in residential aged care:

> *I live in aged care. I need to be able to have visits from my family and friends. I need to be able to visit my family at their homes. I feel that while protecting me from COVID-19, they have taken everything I live for away. (Survey respondent)*

> *My husband suffered a stroke before the Pandemic and moved into aged care. He also suffered depression and over the last two years that got very hard. He could not get used to the new measures, the window visits were a disaster, and he could not understand what was going on. He thought he was in prison. The separation was hard, we had been married 64 years, it seems a sad way to finish a marriage, to end it like that. (Survey respondent)*

A corollary to this is the impact that separation and lockdowns had on the mental wellbeing and health of the spouses who were unable to visit:

> *My spouse is in residential care and both he and I found the lockdowns and inability to visit difficult and detrimental. (Survey respondent)*

> *Having my spouse in aged care caused me great concern. (Survey respondent)*

> *Couldn't visit or support partner in aged care, consequently she declined markedly. (Survey respondent)*

This group relied on telephone calls with family and friends (76%) to stay connected and look after their mental health, reinforcing the importance of ensuring all residents have access to a landline. However, as the CVS co-coordinator noted, *'not every room has a phone of course. You must pay for that service. Lots of people in nursing homes don't have a landline phone.'*[25]

Maintaining social connections was instrumental to staying well, and inability to do so caused much distress:

> *Allow visits from family or a support person to continue as an essential need for aged care residents; allow residents time outside for fresh air and exercise like the rest of the community; recognise that many elderly folk, especially those with dementia, do not know how and cannot remember how to use a computer or mobile phone, and aged care staff do not have time to assist; think about the impact of decisions on other aspects of our physical health, e.g., increased numbers of falls because of lack of exercise. (Survey respondent)*

Not one survey respondent in residential aged care indicated that they relied on access to a mental health professional or service. Residents had very clear expectations and suggestions of what would help:

> *Visitor access and allowed outings in residential aged care. No in-room lock downs for weeks. More staff in aged care. Many shifts are unfilled, and staff don't have time for you. (Survey respondent)*

> *A one rule fits all is so frustrating. In our rural city there was little COVID-19 until Omicron this year, but our Sydney-based directors directed all their facilities to live by Sydney directives. There was no need for us to, for the last two years… Staff absence has been incredible, the justice issue of disgraceful salaries again. Such a learning curve for us all. (Survey respondent)*

> *Having face-to-face visits with my family, consistency in the care staff at my aged care facility, having information communicated to me in a language that I can understand. (Survey respondent)*

Three people of this cohort of 32 indicated their preferred language was not English. It is difficult to identify people from specific backgrounds, as to get a clear picture, we need to ask questions related to ethnicity, place of birth, duration in Australia, English proficiency and preferred languages. This information is crucial as people from CALD backgrounds encounter systemic barriers that increase their vulnerability.[26]

Given this vulnerability and the lack of survey uptake by people from CALD communities, we tried to conduct follow-up interviews with nursing home residents via focus groups. We organised face-to-face interviews through the community services visitor coordinator. It was important that the manager of the aged care home had a good working relationship with, and trusted, the coordinator who set up these focus groups.

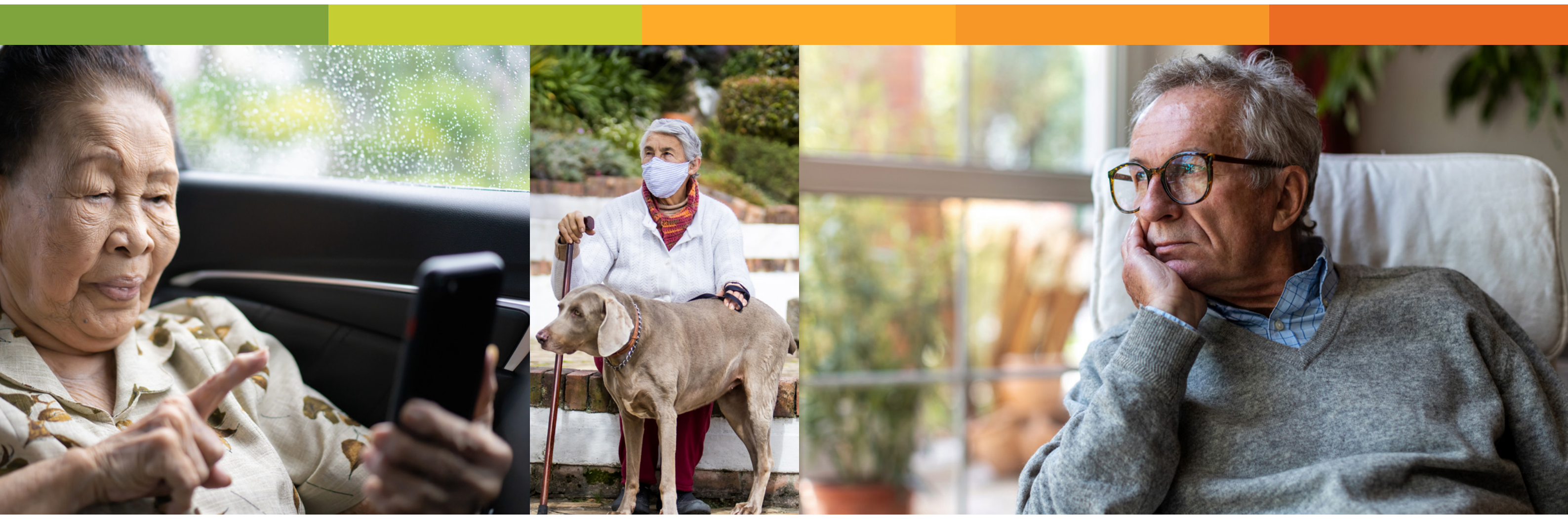
While wary, the three people interviewed spoke of lockdowns and of being confined in their rooms. All relied on regular contact with family members to feel well. Two relied on phone calls, and one used an iPad to connect with children and grandchildren.

They spoke of extreme loneliness, but also of receiving good care from staff and the manager. It was only when we asked what they observed in their less resilient friends/residents who may not have the same family connections, that they allowed their distress to show. One cried:

> *It was terrible, terrible. So lonely. Alone all day in my room. (Interviewee)*

When asked if they know of any services to support older people's mental health, none of them could say what was available:

> *What is it? What kind of help? Mental health help? What is that? (Interviewee)*



All three interviewees said they relied on their families for support and information, and had no need for any other help, but also acknowledged:

> *It would have been helpful to talk to someone about how I felt when we locked in. To have someone to talk to about my sadness, that would be good, yes. (Interviewee)*

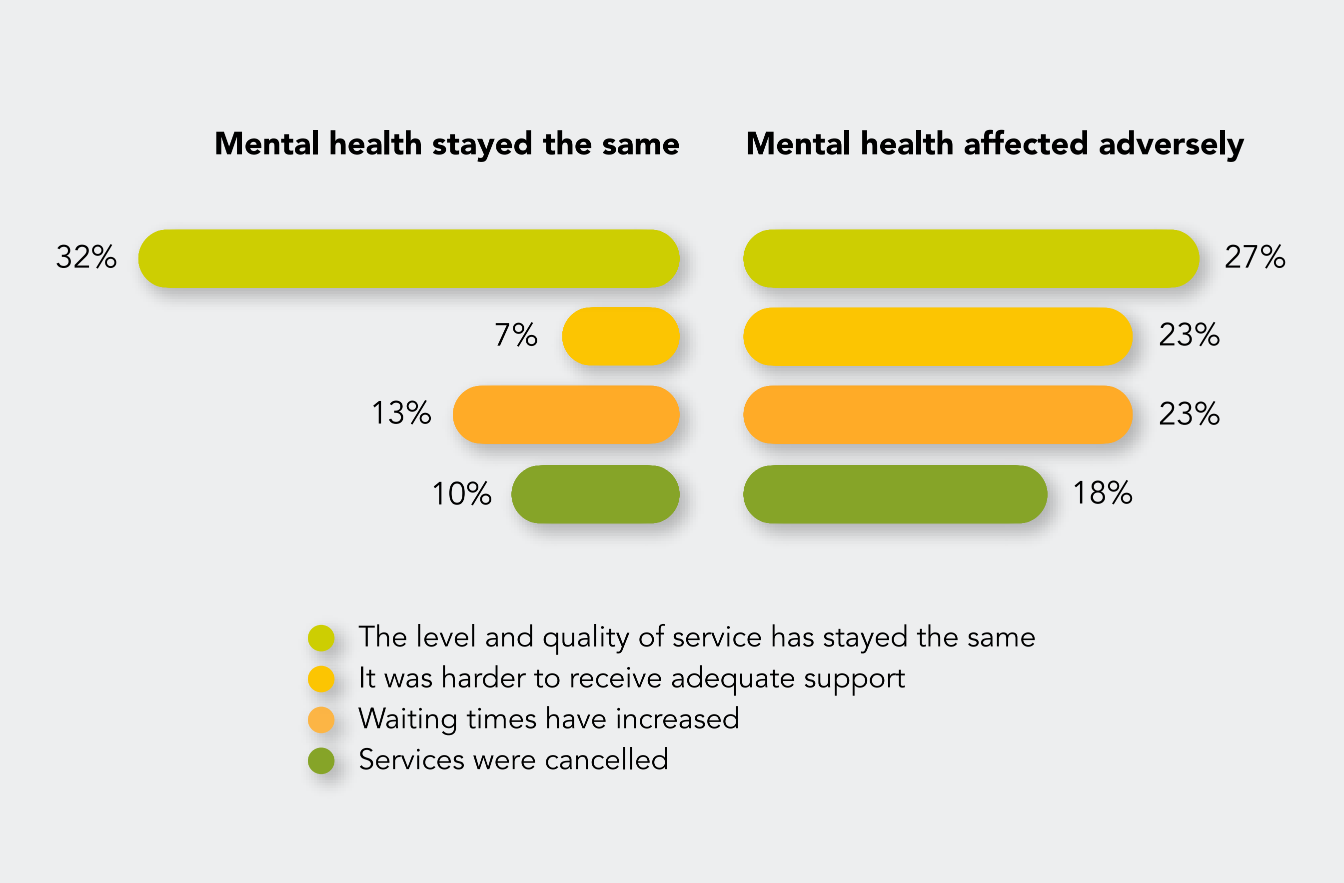
People receiving support services

Support services can range from assistance with cleaning or gardening to more intensive health services required for people to age in place, and maintain a degree of independence, health and dignity. Many providers struggled to find staff and fulfill demand during periods of lockdown, and this affected service availability and quality to consumers.

Overall, of 1,104 respondents, 63% did not receive any home care services; of those that did, less than one third of respondents reported that the level and quality of services they received stayed the same during these periods. The detrimental impacts were particularly experienced by respondents whose mental health was affected during the Pandemic, who reported that they found it harder to receive adequate support and were affected by increased waiting times and cancelled services (see Figure 11):

> *The shortage of staff of the provider has resulted in cancellations of my helper; constant changes of time which finally caused chaos with my other regular appointments; roster changes causing having to change medical appointments or do without a Home Help; changes of staff meaning frequent need to explain what needed to be done and how. NOT the provider's fault, they did their best. But stressful and finally chaotic. (Survey respondent)*

Figure 11: Impact on provision of care services – comparison between those whose mental health stayed the same and those who reported adverse effects (n=516)



The profound impacts of not receiving adequate support, a sense of fear and increased frailty were consistent themes across all data sources. This submission, received from a 78-year-old woman spoke of the long-term impacts of not receiving support for home maintenance, which meant she took on the repairs herself, resulting in an accident. It demonstrates the interrelationship between home support, physical mobility, mental health and the possible long-term consequences of having to move home – the fear and vulnerability of many older people, particularly in times of crisis:

> *I have found myself frustrated because I could not get help from Aged Care to do my gutters or tree pruning. It was promised in February and I am still waiting. However, it meant that I was pushed to do some pruning myself and as a result, injured my back and shoulder and so for two months have suffered pain and lack of mobility. This makes me angry and sad. I have no children in the town in which I live, and I am now considering what my future will be. I want to stay in my little home. (Submission)*

For others, the lack of support created a fear of future frailty and loss of independence:

> *I hope I can get nursing help at home. Any home help would be preferable to going into care. My mother and my mother-in-law were both in nursing homes and knowing the way they were treated, I think I would end my life rather than be faced with that existence. (Submission)*

In focus groups, people also spoke of the connection between the need for physical safety to ensure mental wellbeing. Ageing in this context is related to physical frailty, and the relationship between this and mental distress is clear:

> *Why are you just focusing on how we feel? It's not just about how we feel, it's also about the services that we get. If [during lockdown] an 85-year-old woman, living on her own, cannot sit outside in her garden because it is covered in leaves and she cannot get home services to clean up the back yard, then this will cause distress. She will fear slipping. It will make her depressed. It is a small thing, but it has big impacts. (Focus group participant)*

While the lockdown periods may have created worker shortages and stresses for providers, for aged care package recipients, it exacerbated a lack of agency, choice and control in receiving help with their mental health. They highlighted problems associated with funding and inadequate consultation and unskilled staff. While these may have pre-existed the Pandemic, they continued to have detrimental consequences for recipients:

> *I did not feel supported or understood by aged care package providers. I know what I need to help me stay well. (I was a psychologist for many years.) What had been approved earlier in the package was questioned by new staff with little (or no) understanding of mental health. It is distressing to be told that allied health supports that I rely on are being called into question without me being included in the discussion – particularly when there is more than enough money in the package to fund them. I'm aware that my comment is not entirely COVID related, but it happened to me during the lockdown period, and I came very close to the edge…with no advocate it feels hopeless, and I felt helpless. Aged care providers need to understand mental health issues or have the good sense to call on experts to help them. I don't feel optimistic. (Survey respondent)*

People living with dementia

The AIHW estimates that in 2021, around 386,200 people in Australia lived with dementia, including 243,200 women and 143,000 men. This is equivalent to 15 people with dementia per 1,000 Australians (18 per 1,000 women and 11 per 1,000 men). The rate of dementia also rises quickly with age – from 68 per 1,000 Australians aged 75–79, to 399 per 1,000 Australians aged 90 and over.[27]

The analysis below is based on the responses of 28 people who identified as living with dementia, 2.5% of survey respondents. This is a small sample size, and while the information gathered from the survey may not be representative, it does provide some insight into how lockdowns affected a particularly vulnerable group of Australians aged 75 and over. The majority (60%) were aged between 75 and 84.[28] Additionally, 14% also have a disability and 8% identify as living with a mental health condition.

This is also a highly gendered sample – 71% were female, which reflects the increased risk women have of dementia, the leading cause of death for Australian women.[29]

In this cohort, 15% stated that their preferred language for information was a language other than English, namely Italian, Greek or Croatian. Four of the 28 respondents lived alone in their own home with the help of carers or families, and some had caring responsibilities:

> *I live alone supported by Anglicare services. A niece is my EPOA[30] and does my shopping and looks after my affairs. I also have a grandson who has an intellectual disability who is here most days. He is challenging in many ways, making things harder. (Survey respondent living with dementia)*

Half (50%) lived in residential aged care, one person in supported accommodation and the rest with a partner or family member.

Those who lived in residential aged care described the worst impacts of lockdowns as separation from family, loss of family support, compounded by a decrease in quality of care from staff:

> *Visitation was stopped, so extra care from family stopped. Staff don't have time to spend with me in aged care. (Survey respondent living with dementia)*

> *Hard to receive family support due to lockdowns. Hard to be supported in residential aged care due to limited staff care. (Survey respondent living with dementia)*

During lockdowns, health services moved online or to telehealth; only one survey respondent found it 'easy' to use these services. Instead, a majority (56%) of people living with dementia reported these measures left them feeling 'more isolated because everything moved online, and this did not work for me'. They reported engaging less with friends (70%), stopping 'doing things I enjoyed' (60%), losing confidence (39%), feeling pessimistic about the future (34%) and finding it more difficult to get to or stay asleep (27%):

> *Poor quality service, isolation during lockdown. Cleaning staff have removed personal items without consent and disposed of them – unreplaceable. Arranged specialist appointments arranged by family to occur by telehealth with family members included occurred without family and unfamiliar/unskilled staff. Personal care and grooming supports reduced. (Survey respondent living with dementia)*

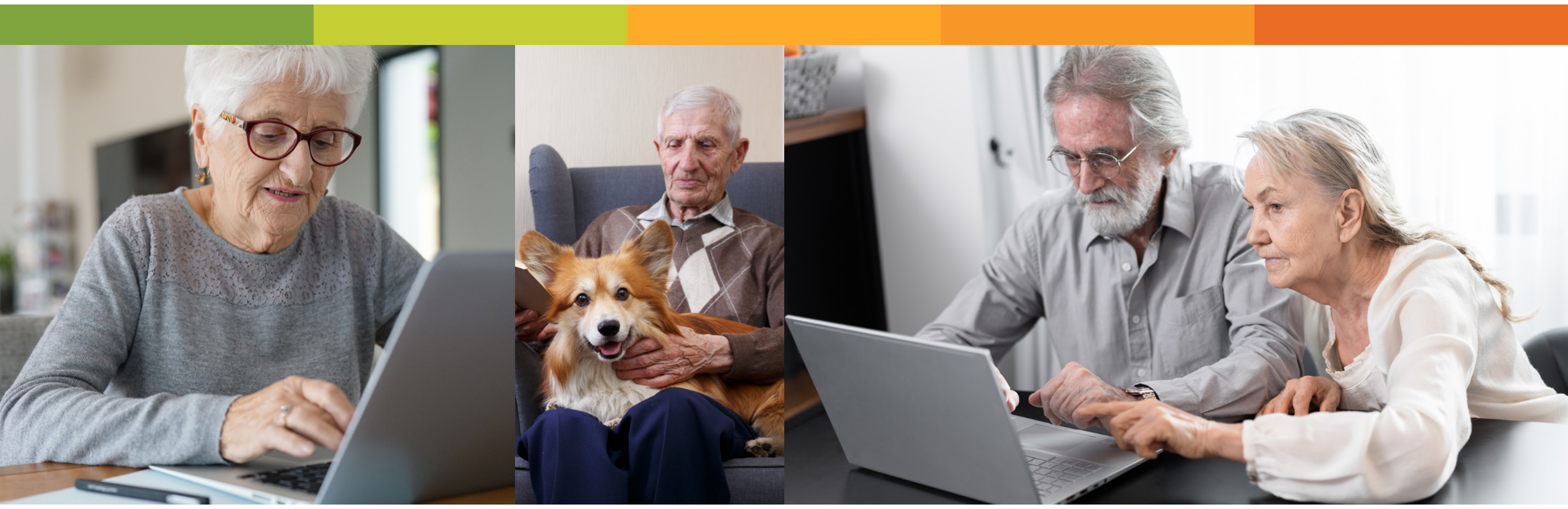
People living with dementia also reported that the Pandemic and lockdown measures had led to a worsening of their mental health (40**%**) and 12**%** reported they experienced mental ill health for the first time in their lives.

This was evidenced throughout survey responses, where:

- **35%** reported that their mental health deteriorated
- **41%** noted changes in their mood
- **59%** became less physically active, and **40%** had no one to talk to, with significant impacts:

> *Lack of fresh air and time outdoors; mental capacity significantly deteriorated. (Survey respondent living with dementia)*

> *My memory and function got worse. (Survey respondent living with dementia)*



The majority do not use mental health services, as ‘they don’t understand the needs of older people’ (27%), or because services are too expensive, unavailable, or not useful. Those in residential aged care faced additional barriers:

> *Aged care facility does not support this. (Survey respondent living with dementia)*

> *These are not offered to me in the aged care home. (Survey respondent living with dementia)*

People living with dementia overall were affected by ‘cancelled community supports and domestic help’, with a third reporting that the worst impacts of lockdowns were that ‘they could not access services they needed, their usual supports were cancelled, and they could not see their GP when needed’.

Separation from family, isolation, missing out on important family events and celebrations, losing social connections, loneliness and missing the funerals of friends and family that passed away were the key impacts experienced by people living with dementia – whether in residential aged care or in the community:

> *Living in aged care and suffering through months of lockdowns, and now being confined to my room for a couple of months because of a COVID-19 outbreak at my facility; my family not even being allowed in to tell me when my sister and only remaining sibling had passed away. (Survey respondent living with dementia)*

The majority (80%) agreed that these impacts on their mental health and wellbeing would be long term. For some people, this was compounded by an awareness of mortality and increasing frailty:

> *Respect and same rules for older people living at home and in aged care. Quality over quantity in our years left is more important. (Survey respondent living with dementia)*

> *This is resident’s final years and spending these years in isolation is cruel and giving residents nothing to live for. (Survey respondent living with dementia)*

Some respondents had strong ideas about what needed to be done differently:

> *Allow more family access to people in aged care. It’s very confusing when the staff keep changing and you never see a familiar face. (Survey respondent living with dementia)*

> *No lockdowns. People die. That’s a fact. But lockdowns are slow deaths. (Survey respondent living with dementia)*

People with caring responsibilities

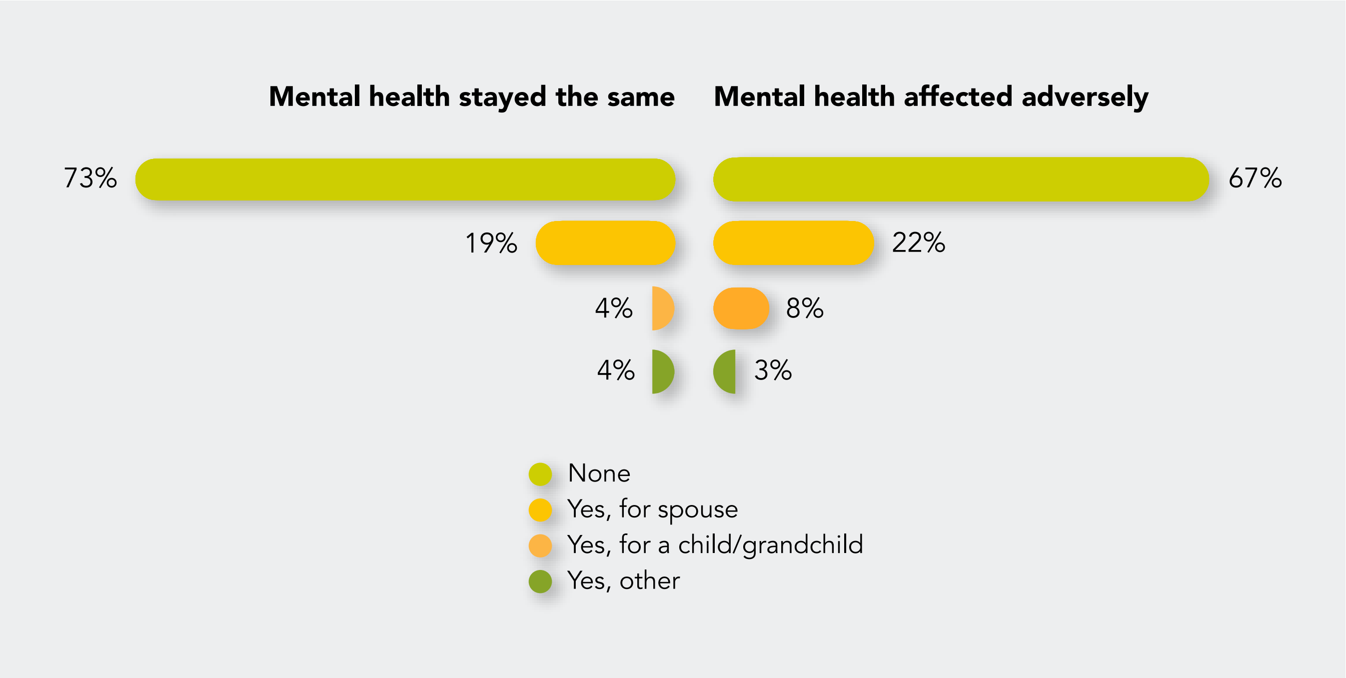
People with informal caring responsibilities were particularly affected by lockdown measures, as support and respite services decreased and the demands of caring increased during the Pandemic. Of 1,119 survey respondents, 323 reported they had caring responsibilities.

The majority (89%) were aged between 75 and 84, and overall:

- **53%** were women
- **25%** lived with a disability
- **6%** lived with a mental health condition
- **69%** had caring responsibility for a spouse, and **18%** for a child or grandchild
- **51%** did not receive any support services, and those who did primarily received gardening, cleaning and transport services.

One third (33%) of people who reported their mental health was adversely affected during the Pandemic had informal caring responsibilities.

Figure 12: Informal caring responsibilities – comparison between those whose mental health stayed the same and those who reported adverse effects (n=1,056)



Of those with caring responsibilities, 12% strongly agreed and 30% agreed that the Pandemic will continue to have long-term impacts on their mental health and wellbeing. However, 29% do not receive mental health support from a psychologist or counsellor because ‘my GP offers enough support for me’ and some questioned the relevance or efficacy of a counsellor given their circumstances:

> *My mental health issues related to the effects of the Pandemic are largely due to my inability to have any time away from being the carer for my spouse who has an incurable progressive neurological condition. (Survey respondent)*

Others referred to the limitations of telehealth, their preference for face-to-face consultations, and their difficulties in finding appointments. Of those who received support services at home, less than one third (31%) agreed that during the Pandemic, the ‘level and quality of service provision stayed the same’. Of those who reported that services had been affected, cancelled or delayed services, increased waiting times and having to pay privately to receive adequate service were the most frequently cited outcomes.

The lockdown measures also meant that for many, respite care for their partners was not available:

> *Respite services at residential aged care homes are not available and accessing specialist doctors is very difficult, if not impossible. (Survey respondent)*

> *My husband was in isolation because he was a close contact while in day respite. Due to staff shortages, cannot increase the respite times. Very difficult to access RAT so he could return to respite. (Survey respondent)*

> *Needed to get husband to hospital, he was moved to a private hospital before code brown. Am really worried how we will manage when home. (Survey respondent)*

The impacts on the health of informal carers were articulated clearly in submissions and focus groups:

> *Due to cancellation of services for my husband and son I had to take up the responsibility to meet their needs at the same time my own physical health started to deteriorate. (Survey respondent)*

And a loss of oneself:

> *I am now not a wife or a person with a life, I am just a full carer for my husband. (Survey respondent)*

The single most cited service that would help carers was respite, for both the person being cared for and for the carers:

> *Availability of respite care for my wife so I could get away for a break. Carer support groups. (Survey respondent)*

> *Some form of respite to provide time out from caring. E.g., someone to sit with the person needing care to give the carer time to themselves, plus somewhere for the carer to go. Hard in lockdown, cannot meet with people or go for a coffee. (Submission)*

> *Someone to check if I’m still alive regularly so my dog is looked after. Being able to see my wife who is in lockdown in aged care facility. Married for 60 years. (Survey respondent)*

My Pandemic Story

My story began when I became a carer for my husband who had multiple health problems… The stress took a toll on my own health, and I had bouts of depression… My husband began to have delusions and as a result became verbally and emotionally abusive. He needed [two major operations]. He also had a diagnosis of emphysema, and I became more and more stressed. Then…COVID-19. Living in [state] I was fortunate, but then I had an incident when my hand slipped on a wet rail exiting a swimming pool. I had a complex broken femur and spent nine weeks in hospital. I was not allowed to put any weight on my broken leg and because of COVID-19 restrictions, I spent a lot of time in quarantine.

Every time I was transferred to a different facility, I gained another 14 days quarantine. I came home and took on my caring role again. It was a huge challenge as I was lacking in mobility and my husband was diagnosed with vascular dementia shortly after. Then another bad fall, I broke the same femur again and spent more time in hospital and rehab. On doctor's advice, my husband was admitted to a nursing home due to my health and mobility problems. My husband passed away and I needed help that was difficult to access. I relied on paying for essential assistance myself.

An aged care assistance assessment identified I needed a level 3 package urgently but waiting for the necessary assistance took quite a while. As a result, I struggled with depression and felt isolated. But I was fortunate to be naturally optimistic… I received counselling, volunteer home visits and a subscription to online concerts gave me strength to battle the depression. I now manage much better as I can leave my home independently. I am grateful that [state] did not have the restrictions other states had. I am confident that whatever COVID-19 deals out, I will manage with help and a positive mindset.

(Submission)

Older Australians from CALD communities

The term CALD (Culturally and Linguistically Diverse) is a contested one. While it is used as policy shorthand for the multicultural richness of contemporary Australia, it can elide the complex lived experiences of pre- and post-migration, history and arrival, refugee status, ability, gender, privilege and disadvantage of Australians. In the context of this research, we use the term CALD communities to present the experience of older Australians aged 75 and over from Italian, Greek, Vietnamese, Chinese and Egyptian backgrounds.[31]

In the survey, respondents were given the option of identifying in which language they preferred to receive information. The overwhelming majority (98%) chose English, so we have little quantitative data on CALD communities, but detailed qualitative data from focus groups and interviews.

While diverse in language, gender, religion and experience and arrival status in Australia, the focus group participants expressed similar themes. These are explored further throughout this report, but can be summarised as:

Distress caused by loneliness and isolation

> *Yep, I could see there were many elderlies who felt sad even though they joined the groups on Zoom. They said they felt bored and didn't want to live anymore. They felt that life is useless, and nothing could make them interested to live. Then, I spoke to them and told them that there are many… people who are still trying to survive and we are luckier than those ones, we are living in good conditions, good environments and in a good country as well, why didn't we try to be optimistic and be happy for what we have? (Interviewee)*

Little or no engagement with official information sources about the Pandemic, lockdown measures and how to look after their health

Their sources of information were news (television) from Greece, Italy, Arabic language news, Vietnam, and in a language and format they could understand:

> *The information that I could get are all from my daughter. There are no one else that I know could help me to get any information. (Focus group participant)*

> *We used WeChat for some information. We could only read a little bit of it. If we read too much, we might get more confused. (Focus group participant)*

The Pandemic brought up past trauma (in CALD communities especially), to do with migration, pre arrival experiences and racism:

> *There are some people that really need help, they are often feeling blue, they often feel sad and disappointed. They often think about the pasts. They worry about everything, that what if they pass away, who is going to care for their graves. (Interviewee)*

> *I used to live in the time of the Great Vietnamese famine of 1945, so now I am not afraid of anything. Even now if there is a case of no food I can still survive. I have no problem dealing with the Pandemic, but there were many friends who called me…they often called and asked about dealing with mental health… They talked to the psychologist, but they couldn't fix the problem. (Interviewee)*

Some participants recognised the mental health impacts of bereavement, grief and disconnection from usual mourning and support processes and connections:

> *Not only I felt frightened and vulnerable, but also suffering from grief and lost. I now have to ask my daughter sleep with me every night, as I can't sleep on my own, I am so worried about that at any night I might dying without any help. (Interviewee)*

> *My beautiful bride, my Madonna, she died and I could not be with her in hospital. On the last day they let my son take me so I could say goodbye through the window. After 75 years together, she died alone and I grieve alone. (Focus group participant)*

Reliance on support from community-based organisations

The importance of culturally informed, responsive, and appropriate care – particularly for groups where the concept of mental health is an unfamiliar one – was also highlighted in focus groups:

> *Not aware of any services for mental health. Not aware of any services for older people experiencing distress during the Pandemic. (Focus group participant)*

> *In our country we were told fix yourself. Australia is different, everyone has equal rights to services, but we senior people need help to access these services. (Focus group participant)*

Discussions with the regional CO.AS.IT. coordinators, MCWH bilingual educators and Australian Greek Welfare staff further reinforced the need for culturally safe models of mental health education and support, integrated into existing service provision. As workers from the MCWH reported:

> *People need help – they need to know who they can talk to but will not ask it in public. If you build trust, then they will talk about anything. Older people need to be comfortable and feel confident, not confronted. The language of mental health does not work, and diagnostic labels do not translate easily, and may have no cultural or language equivalent. They will hide mental health issues to avoid family conflict and make them feel more comfortable. For some communities, it is shameful to talk about mental ill health.*

2. Communication: Information provision was not adequate

Communication in times of national emergencies such as the Pandemic is important. Getting the right information to the right people in the right way is even more important.

The significance of appropriate, consistent, and accessible information was a strong theme in this research, and was evident in survey responses, focus groups, interviews and submissions. Through the survey, 57% of respondents overall agreed that 'knowing what to do to stay well and healthy' would benefit their mental health, with devastating consequences for those who did not receive the information they needed:

> *I was told briefly by phone that one of my aged care workers had COVID-19, but I was not told how to care for myself or my husband, what precautions I should take … NOTHING. I was scared and confused as I am also immune compromised. (Survey respondent)*

> *Goodness, having seen the way the government makes decisions one might be really dejected. I think the hope comes from better communication from organisations like COTA and others that can engage with different parts of the community. The people must take more control and be given a better voice. (Submission)*

Where did they get their information from and how effective was it?

The survey data tells us the main sources of information about the Pandemic were:

70%	Television news
45%	Government briefings and announcements
45%	Print media – for example newspapers
38%	Radio
31%	Family members
28%	Healthcare professional, such as my GP
23%	Department of Health website

A majority (60%) of respondents (n=1,088) considered this information to be mostly relevant and useful. However, for many Australians aged 75 and over, the information they received about the Pandemic, how to look after themselves or where to go for help was also 'inconsistent', 'not relevant' or inadequate, particularly among those who considered their mental health adversely affected. Having the right information for self-care from reliable, trusted sources was important. People who reported that their mental health was adversely affected during the Pandemic were more likely to perceive the available information as confusing, not helpful, inconsistent, or politicised:

> *I got myself out of a depressed state by stopping watching mainstream media. The continual number of COVID-19 cases was just ridiculous. The reporting was biased and not truthful. I turned to Classic FM to provide minimum news updates – only listened at 7am in the morning and then watched the local TV news at night. (Submission)*

The perceived lack of information and a coordinated approach, combined with relentless media reporting, was not conducive to mental wellbeing, and was a key theme in many of the submissions received and responses to open ended survey questions. As one submission noted:

> *As to my mental stability, I did talk to my pets a lot and my one neighbour over the fence… I feel the initial panic, government and media overkill influenced me, making me anxious, worried etc. It was a constant source of doom, gloom and horrendous stories of death, separation from family and worldwide horrific statistics. (Submission)*

Timely and appropriate information was seen as facilitating self-reliance, getting on with it, and the resilience built over a lifetime:

> *With bushfires, I know what to do. I have all the information I need to take care of myself in that situation. I don't have that information for the Pandemic. (Interviewee)*

A significant proportion (64%) of people who responded that their mental health was unaffected by the Pandemic identified 'knowing what to do to stay well and healthy' as the strategy that helped them most over the last two years; in contrast, only 42% of those whose mental health deteriorated identified that same option. This was also a consistent theme in submissions and the qualitative responses elicited through open ended questions:

> *The [information] was sometimes relevant and useful, many times some sources contradictory with others which led to confusion and the possibility of more dramatic interpretations. (Survey respondent)*

> *Nothing about what to do if you get COVID-19…info from provider was all about how they were protecting themselves from COVID-19. It was very confusing; it is still very confusing. What happens if I catch COVID-19, where will I call, what will happen when I call, there is very little practical advice given by anyone. (Survey respondent)*

Many older Australians suggested that much of the communication about the Pandemic and lockdowns justified age-based measures that pitted generations against each other:

> *The emphasis on age and underlying conditions in Pandemic warnings and reporting has been hurtful and had allowed a general sense of older lives being expendable and less valuable as if it doesn't matter to anyone if we die earlier than we might have without COVID-19. The messaging has resulted in younger people not really caring about older people. (Survey respondent)*

> *There is a feeling that the government has thrown us under the bus – that it's all too hard. No recognition of the needs of elderly people. (Survey respondent)*

This understanding that ageism has informed the narratives around older people and the Pandemic has been well documented, and is evident in official narratives as described above, to cultural tropes such as 'boomer remover', and the assumptions of 'age-appropriate stoicism and depression' in older people. Interviewees also raised the potential dangers of 'age appropriate and expected' resilience and stoicism, particularly from service providers and carers – and how this may be underpinned by ageist assumptions. This is consistent with international research indicating that 'older people with mental health conditions and long-term care residents have been particularly affected by ageism and discrimination during the Pandemic'.[32]

A strong body of research suggests that during the Pandemic, 'ageism has been manifested in the discourse around older people as vulnerable, worthless or a burden to society as well as in measures aimed to protect older people, yet, restricting their rights and depriving them of their freedom'.[33] The lived experience of many Australians aged 75 and over reinforces that the impacts are very real and very distressing, and need to be addressed by:

> *Clear instructions on what is happening and what is required for the good of everyone. Adequate help and consideration for the most vulnerable in our community…those living with disability, indigenous Australians, the homeless, the disadvantaged and the aged so that they do not become dispensable statistics and their needs are taken into account before they are pushed aside to become the collateral damaged in favour of the economy…Life is precious to all and should not be undervalued. (Survey respondent)*

A consistent theme was also the perceived politicisation of communication during the Pandemic:

> *Governments might get down on the ground, they might consider that their policy announcements don't mean that the measures are in place or that there are staff to carry them out or that staff understand what is required. I've given up on listening to the endless announcements. When I see a press conference announced I turn to my classical music station. Hopefully, I am getting closer to the 'I don't really care' position… Sigh!!! Patience, tolerance and much meditation. Ohm! (Submission)*

Instead, what was needed was:

> *More clear info for vulnerable older people, and what is safe to do and how, or whether we should just stay at home. Not letting COVID-19 rip and acting like older or vulnerable people are just death statistics and it's OK to die so that young people can have freedoms. (Survey respondent)*

CALD communities and information

In focus groups, we heard that people from non-English speaking communities relied on direct news and media reporting from their countries of origin in their first language, whether through Arabic TV, Italian news media or Chinese language platforms, despite this not being information about the Australian context. This has resulted in a lack of information, and ongoing fear and confusion:

> *People are very confused with the available information. Are we out of it? (Focus group participant)*

> *We might think it looks like it is over, but we don't believe the Pandemic is over. People are still isolated, still suffering, too scared to go out. It is not like the war is over, it is all over. Not OK. (Focus group participant)*

Some community-based CALD organisations mobilised to provide information to consumers:

> *The Pandemic certainly created problems. It was a lack of communication, a lack of contact. People who were connected to Greek welfare, if they had that support, they were better. (Interviewee)*

We heard from CALD focus groups that community leaders sent updated information via Viber, while other sources of information were social media apps, YouTube and Facebook, in language:

> *I like to use my WeChat app on my phone, I do not use any official website in English. (Focus group participant)*

> *I listened to SBS radio in Chinese, and I watch Channel 7 at times. For international news, I watch news form Taiwan as well as news from CCTV.*[34] *(Focus group participant)*

There was little or no engagement with official information sources about the Pandemic, lockdown measures and how to look after their health. Their sources of information were news (television) from Greece, Italy, Arabic language news, in Vietnamese and in a language and format they could understand:

> *My husband read the information on the internet, and he told me what he heard/read. He watched YouTube in Vietnamese. I don't know much about English, so I preferred information translated into Vietnamese. (Focus group participant)*

> *It's very good that AVWA*[35] *often sent the information via Viber. (Focus group participant)*

Family members were also a key source of information:

> *My children watch News on TV, and I got the information from them. (Focus group participant)*

> *The information that I could get are all from my daughter. There are no one else that I know could help me to get any information. (Focus group participant)*

The issues of punishment and retribution were discussed in both the Italian and Chinese speaking focus groups, where there was a perception 'that if you were infected, then you would be left to die'. Bilingual workers reported that during focus groups, participants articulated the fear that 'if they allowed visitors into their home, they would be punished, or left to die by government for not following rules'.[36]

The positives of communication

Some people reported that they were happy with the amount and quality of information they received about the Pandemic, most often provided by trusted sources such as the ABC, particularly journalists with medical expertise such as Dr Norman Swan, and Premier announcements.

Trusted sources of information for people from CALD communities were different. As many had limited English proficiency and digital literacy, they relied on family, media in their own language and on their community representatives to provide adequate information:

> *Yes, I have got enough information. It's very useful information. The group leaders from AVWA*[37] *often updated news via Viber. They sent messages to the whole group via Viber. They advised what we should do during the Pandemic, e.g., wearing masks, where to get help and support etc. I got the information from the GP as well. He gave me the phone number that I can call him at night. (Focus group participant)*

> *I did feel frightened and vulnerable, however the social media WeChat was a good way to keep me in contact with my friends. We are meeting online once a week to catch up with each other, pass on the useful information. (Interviewee)*

Case Study: Engagement with CALD communities – St Mina Orthodox Church Seniors Group, Hallam, Victoria

One example of a targeted and effective information and engagement strategy was provided by members of the St Mina Coptic Orthodox Community group in south-eastern Melbourne. The group has over 140 members, with the majority aged over 70, Egyptian born and Arabic-speaking.

During lockdowns, the group facilitator organised a series of webinars to provide accurate information about the Pandemic, vaccinations and appropriate health measures. Speakers included a trusted local GP, Department of Health representatives and researchers from Monash University School of Public Health and Preventive Medicine. Professional translators provided translation into and from English and Arabic.

To promote the webinar, the organisers printed a flyer in Arabic and posted it to all members. On the flyer was a link to the webinar and the group's YouTube channel. The purpose of the webinar was discussed on Arabic community radio and TV.

The next stage was crucial to the success of this strategy. The organisers also connected with the family of each individual member of the group – often grandchildren – who could assist their parents or grandparents with accessing the webinar, ask questions, or later watch it on YouTube. For those who lived on their own, the organisers contacted community visitors or carers to assist with access.

Focus group participants considered this webinar to be instrumental in their receiving helpful and useful information, and as the recording is still available on YouTube, it continues to be a source of information. The success of the engagement strategy led to other interventions, including online exercise classes using Zoom, so that participants could engage with each other while also keeping physically active. Once again, family members were recruited to ensure that technology and literacy were not barriers to access.

3. Understanding of, and engagement with, the formal mental health system

There is a lack of information and knowledge about, and engagement with, the formal mental health system

> *What would help? Easier access to mental health plans. Skills to ensure that this Pandemic does not become a platform to justify the rejection of the aged and disabled. (Survey respondent)*

During the Pandemic, a range of government and health sector initiatives aimed to address the Pandemic-related mental health problems by increasing the availability of, and access to, mental health services. However, research by Monash University suggests that only about 11% of Australians used these services.[38] The research is limited as it does not provide a detailed breakdown by age (using only the category 55+).

Australians we surveyed, aged 75 and over who are mostly English speaking, educated and digitally literate, engage with the formal mental health system at much lower rates than the 11% cited by the Monash University research.

Only one survey respondent referred to the Older Persons Mental Health Service in their state.

Use of mental health services

Survey respondents were asked who they reached out to for help with their mental health. Most (98%) of respondents who had not experienced adverse impacts during the Pandemic had not used a mental health service, mostly because ‘I don’t need them’ (78%) or because ‘my GP is enough’ (25%).

The majority (88.5%) of older Australians who reported that their mental health had been affected during the Pandemic also reported they did not use these services, but for different reasons, including cost, accessibility and usefulness:

- **31%** because they don’t need them
- **20%** because their GP is enough
- **18%** found mental health services too expensive
- **20%** because these services don’t understand the needs of older people.

For some, the motivation and work involved in finding an appropriate mental health service while depressed was too difficult:

> *During the Pandemic I was depressed and anxious. I was not in a place to go to a psychiatrist or psychologist. The big problem was loneliness. (Survey respondent)*

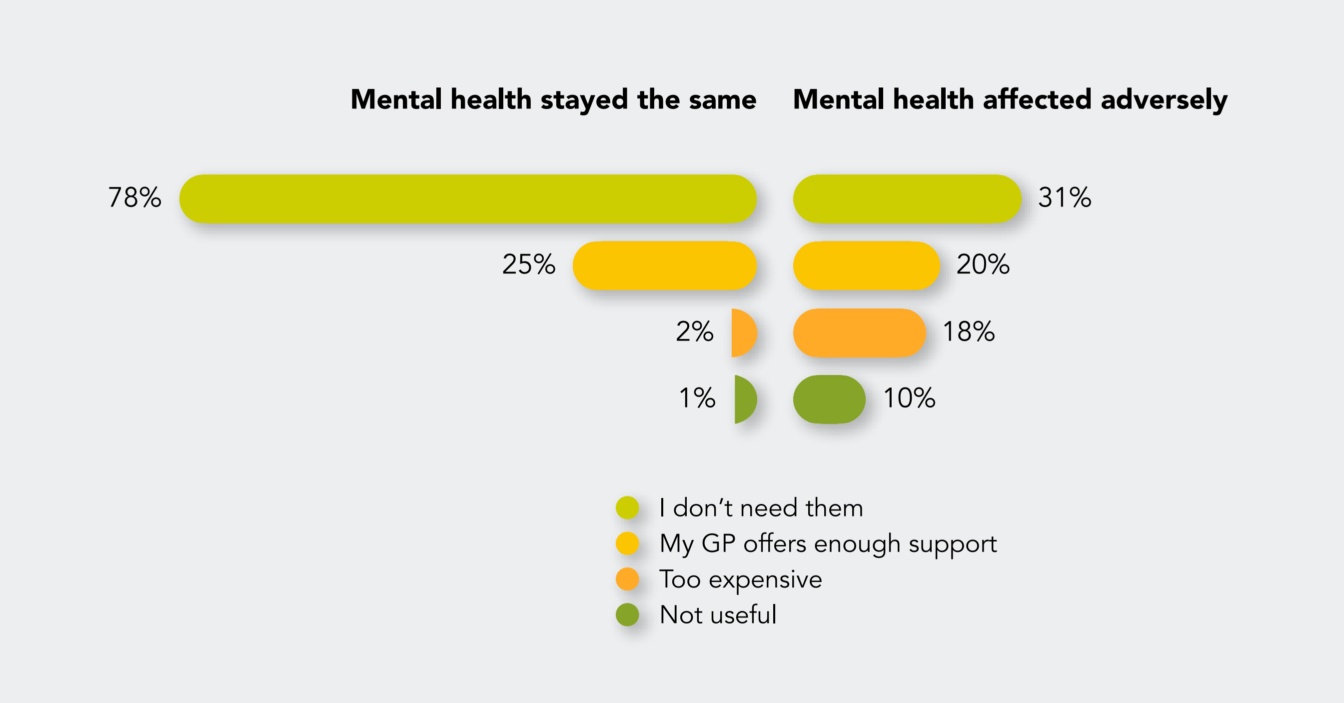
Additionally, some described their mental health struggles as situational or exacerbated by the Pandemic:

> *My partner died suddenly just before COVID-19, so it was very hard to grieve at the same time – like a double dose of something awful. (Survey respondent)*

> *Separation from my spouse is the main problem, a counsellor can’t resolve that. (Survey respondent)*

This is supported by research suggesting that most people ‘do not see themselves as needing psychiatric services, or that these will address the problems they are experiencing, such as having to close a business, lose income or a job, social isolation, cancelled family events, and the burden of unpaid caregiving’.[39]

Figure 13: Reasons for not using mental health services – comparison between those whose mental health stayed the same and those who reported adverse effects (n=985)



While the survey could not capture the cultural and linguistic diversity of older Australians, the interviews and focus groups did try to address this. In the Italian speaking group, no one had used or was aware of mental health services or professionals. Similar responses were elicited from the Chinese, Vietnamese, Greek and Arabic speaking Coptic groups. The reasons are many and include:

- stigma associated with mental illness
- not knowing where to access such services – or of their existence
- preferring to use the services of a trusted GP
- perceived cultural inappropriateness of the services
- the difficulties of using an interpreter in such settings
- a reliance on and preference for family support.

> *As I told you, I am a type of optimistic person, so I don't need help from psychologists or any kind of mental help. My children are all grown up. I have nothing to worry about. If there is anything I need I may just ask my family doctor. (Focus group participant)*

> *When I am unhealthy, I just go to the doctor. He gave me the best advice. If there is anything more, I would ask my friends. There is no need for me to go to ask for help elsewhere. (Focus group participant)*

> *Maybe, if they speak Chinese. I never know these services. (Focus group participant)*

The social stigma surrounding mental health issues and services, combined with a lack of reliable trained bilingual and bicultural practitioners and services, can severely limit access to support.[40]

Improved mental health literacy

Not one interviewee in residential aged care had received or knew of mental health services and support available to address the impacts of the Pandemic:

> *What kind of help is that? I didn't know it existed. It would have helped me to have someone listen to my sadness. (Focus group participant)*

Similarly in focus groups, few participants knew of mental health services, or would acknowledge publicly to having the need for one. One participant in the Vietnamese group had been referred to and consulted a psychologist and would do so again if needed:

> *I can check my health with my family doctor via phone. I had eye health issues, so I was very sad, the family doctor called me and suggested a Vietnamese female psychologist. I called her and talked to her on the telephone. It was a useful session for talking about psychologies. She gave me some useful advice that made me feel better. I just tried one time and I felt it was pretty good, I felt better. I will call back later once I need it. (Focus group participant)*

Additionally, survey respondents and interviewees referred to a scarcity of appropriate mental health services for older Australians. This, combined with what researchers have identified as 'a strong association between mental health conditions and ageism' leads to demonstrated poor health outcomes.[41] In interviews, we heard of the 'Inadequacy of mental health services' from older Australians with lived experience of chronic mental ill health, who suggested that was needed were:

> *Mental health experts who are also trained in gerontology, and aged care workers should be trained in mental health. After all, these are the people doing the most intimate and necessary tasks for you, they are in your home every day. They could receive the same training as Beyond Blue or Lifeline staff. (Interviewee)*

> *I think more psychologists. Psychiatrists, all they do is prescribe medication. They do not get the psycho-social stuff for older people. I think more psychologists are needed on the ground. Not necessarily clinical psychologists, but counsellors. (Interviewee)*

Others spoke of services and campaigns that focused on the mental health needs of younger people during the Pandemic:

> *...there is a lot for teenagers, much less is available specifically for older people. And I have a heartache, that younger people are missing out on life, they have missed out on so much, but [older people also] need to talk to a 'real' professional, not someone who has been trained to answer the phone at Lifeline or Beyond Blue. (Interviewee)*

The language employed by mental health services does not resonate with this age group, so different ways of communicating the symptoms of mental ill health and distress may be required. Two interviewees raised the possibility of a targeted education campaign around mental health that not only addresses stigma, but also provides information about resilience, strategies for coping and where to go for help:

> *You need to make people aware that stress, especially for us older people, is a mental health problem – they just don't understand that. What we need to do is provide ways for people older people to recognise impact of stress on their mental health. (Interviewee)*

> *My generation seldom go for such services. (Survey respondent)*

> *Can't look at mental health in isolation. People don't see stress as a mental health issue, and what it brings on. (Interviewee)*

Those willing to engage identified a lack of appropriate, affordable and available services as a barrier:

> *We need easier access to mental health practitioners. The one person who was able to really help me there can't be funded through Medicare nor through my health fund, so I need to pay and don't get any reimbursement. Of course, as a pensioner, I can't afford to do this often enough to be helpful, so I don't do it at all. (Survey respondent)*

> *I [received] a referral from my GP to a psychologist and searching out another who was better and was cheap enough for me to pay for a few sessions. My health fund did not reimburse me for this service. (Survey respondent)*

> *These services are not readily available in country areas. (Survey respondent)*

During the Pandemic, many services that may have provided support for older Australians experiencing distress moved online. Such interventions, while aiming to increase access to services, may not be appropriate strategies for older Australians. Some participants expressed concern that these led to more isolation:

> *I am concerned that people living at home have fallen through the cracks as services have gone online and this is not accessible for a lot of people. I really feel more can be done to connect family members with their loved ones. Technology is not really an option. (Phone interviewee)*

The long-term mental health impacts of the Pandemic are undetermined. COTA Australia's research suggests that to mitigate these and prevent long-term mental ill health, improved mental health literacy and education around evidence-based coping strategies and resilience building are urgently needed. The focus needs to be on what can be done to support people during lockdowns. There must be understanding that responses are not pathological, and recognition that isolation and loneliness are normal feelings and reactions to lockdowns.

> *It is shameful to talk about mental health, and distress of not coping. (Interviewee)*

> *Don't want to cause distress and shame to families who may not be able to help. (Focus group participant)*

Although older adult patients have many of the psychological needs that other age groups have, they also have unique mental healthcare needs.

> *'Understanding age differences in mental health interventions is important to design treatments to optimize its implementation among older adults.'*[42]

Ageism informs service provision and, while ageism affects everyone across the lifespan, for older people it can lead to inadequate and disrupted services and experiences of the mental health system, and must be interrogated:

> *The Pandemic highlighted mixed emotions over longevity. Confronting mortality while in isolation is a huge burden on peoples' wellbeing. You can't address people's mental health and wellbeing if they feel their lives don't matter. Must address underlying ageism and the fear that only younger people's lives matter. (Interviewee)*

Interrogate the privileging of resilience and stoicism

The theme of resilience earned from a lifetime of stoicism, of wisdom imparted by age through survival of 'wars, famines and difficult circumstances', was evident in all the data sources:

> *Like most people my age and those born in the 1930s, there have been some world shattering times, even in Australia WWII had its effects. I was widowed in my late 30s and with 2 young boys to bring up, new car I could not drive, a just finished dream home and a small retail business I was going to have to run… I developed a strategy to cope then and have used it ever since… I thought of a worst-case situation, dear ones tortured etc, all the things I remember people in WWII putting up with and I resolved while that was not happening, I would be, if not happy, I would be grateful for how things were for me…and it has always worked for me. So just went with that strategy. Sometimes I would just have a long loud private swearing session. (Submission)*

'I don't need it', was the top reason cited across all cohorts for not using mental health services. As one interviewee noted,

> *It is a fine balance between recognising and supporting people's resilience and using it to justify inadequate or insufficient services. It means that resilience and stoicism are privileged, and age-related trauma and distress are minimised. We need to challenge the assumption that older people don't need mental health support, that a lifetime of resilience is protective, and the dismissal of anxiety and depression in older people as age appropriate. (Interviewee)*

The data shows that, in times of national crisis such as pandemics, this minimisation, along with the lack of appropriate mental health services, has devasting mental health impacts on older Australians.

Impacts on families and connections also affect older people's mental health

There is a need to address the impact of the Pandemic on family, family dynamics and especially for those who rely on family, who have caring responsibilities, or whose families are their only conduit to information. During the Pandemic, the wellbeing of older people did not exist in isolation, but in relation to the wellbeing of others, including friends, carers and particularly family and grandchildren:

> *I do not want to add stress to the family as the worst thing has happened to us, my eldest grandson, 17 yrs, a bright boy who got a 1/2 scholarship to a good school a couple of years ago, due to go into year 12 next year, has left school, he is very depressed, is cutting himself and has been both an outpatient and inpatient at a psychiatric unit, however his parents cannot get him in to see a specialist or get medication for him as they are not taking any new clients! This is a shocking situation for them to be in, and I feel so useless to help. So, this is my COVID-19 story. (Submission)*

During interviews and focus groups, older people spoke of their concern for family members during lockdowns, and the distress this caused:

> *My cousin has schizophrenia, and he will not go out without his brother. They felt isolated because they could not go out, but also stressed because they could not go out… My daughter is a breast cancer survivor. But during COVID-19 she could not get an appointment for her annual breast scan. Can you imagine that stress and what it did to us? **There were a lot of aspects to the Pandemic – not just what happened to me.** (Interviewee)*

4. Where did older Australians go for help?

Primary care, including community-based support, GPs and trusted service providers, play a key role in the lives of older people. These services were instrumental in older Australians remaining well and receiving support during the Pandemic and lockdowns.

The role of GPs

During the Pandemic, GPs were the first choice of older Australians for advice on physical and mental health. This was supported consistently by survey data, qualitative data including focus groups, submissions, and interviews, and was a recurring theme across all ages, genders and cultural groups:

> *I am amongst the lucky ones who seem to have coped and survived well. The importance of knowing I still could have telehealth connections to my GP whenever required was important to me. (Survey respondent)*

> *When I needed help, I just called my GP. My friends told me they are jealous because my doctor is so good, he is more than what I have been expecting. Anytime I needed help I just called him, even on the weekends. (Interviewee)*

However, what the data does not tell us is what interventions were provided by GPs. Possibilities include medication, referral to mental health specialists and services, and treatment plans, but our methodology did not collect this information systematically. Given the high rates of prescribed psychotropic medications for people aged 80 and over,[43] the lack of engagement with older people's mental health services and general formal mental health services, these referral pathways warrant further investigation:

> *If you can't afford to pay for a private psychologist, and rely on public services, you get nothing. You are lucky to get a 5-minute consultation on the phone at the moment. You are not face-to-face. It is not good enough really. And if they know you have all these pre-existing conditions, then they are not really bothered. I have got a good GP, though it has taken many years to find them. (Interviewee)*

Community-based support

Across all sectors of the Australian community, organisations mobilised to offer support to Australians aged 75 and over:

> *Our community centre still opened once a month and I would have a phone call twice a month from this centre; I would not go online for searching information; I would go to GP's clinic for script and medicine. (Interviewee)*

> *People are social. People want connections, to listen as we speak, to what we think. (Interviewee)*

Many services stopped during lockdown periods as travel and contact restrictions came into force. This meant that community visitors, volunteers, mental health workers and other support providers had to find different ways of contacting their consumers. This highlights the importance of ongoing regular contact, through the CVS, volunteers and visitation programs, including ethno- and language-specific area health workers.

> *I was a bit sad when the Pandemic started, but it did not last long. They deployed Zoom just more than a week after, so I didn't see many changes, we still enjoyed [activities] at home… I and other group members had enjoyed it, but I think for those who did not [get] involved with community groups, it must be different, they must be feeling sad and isolated. (Interviewee)*

Community mobilisation at individual level

There were many examples of individuals and neighbourhood groups organising to contact those that were isolated or vulnerable:

> *My husband has been visiting daily and providing some tasks that our neighbour cannot perform. He is 90 years old and a widower. Recently he was taken to a rehabilitation centre after a fall and my husband has agreed to deliver clothing and other support and visiting a centre which is quite a long journey for him. His son lives in Melbourne and has only seen him a couple of times since early last year. Although we do not mind doing these tasks for him, it is becoming onerous as his son does not seem to be able to be around very much at all. I recently had two hip replacements and removal of a melanoma and find it is getting to be too hard. If he returns soon as he thinks he might, I am not sure we will be able to continue this support as much as we have been doing. (Submission)*

> *A neighbour set up a co-op for our street block. We all said who we are, our street number, what we could contribute and what we needed, so we all now know each other and feel able to seek help when needed. It has improved our sense of community which was already good. (Survey respondent)*

Providing opportunities for talk

People need to talk about the impacts of the Pandemic and need to do this in ways that are familiar and safe. It was clear in some focus groups that these were the first opportunities people had to discuss the impacts of the Pandemic on their mental health, and they considered it important to do it again.

Focus groups, which were conducted face to face, often lasted two to three hours, much longer than the scheduled hour. We heard from participants that the focus group was remedial, that this was the first time they had been asked about their mental health, and they wondered why there were not more opportunities to do so:

> *We should have a small group so that we can have more time to share our stories. In a community group…we did not have much time to talk to each other. We need a small group; we need to talk. Talking and sharing help old people reduce stress. When we feel lonely, it would be great if there is someone who is willing to listen it would help to reduce stress/ anxiety. (Focus group participant)*

Community-based workers have the potential to facilitate such connections and play a stronger role in educating about mental health, what to do and where to get appropriate support. This is particularly salient for organisations that work with older people from CALD communities, who provide support and have an understanding of the specific issues faced by CALD communities:

> *Before COVID-19 there were social groups [through community organisation], these were a way of connection. Must ensure good connection between social and individual situation. It has to come to them in their own homes. (Focus group participant)*

During the Pandemic, the mobilisation of community-based organisations was strong, and many respondents and focus group participants had strong views about how this could be leveraged:

> *Could also link to local government and importance of using local government data to find people who are living alone, may need more assistance etc. (Survey respondent)*

> *A support service that checks up on elderly people who live alone, especially the ones who do not have any relatives around. (Survey respondent)*

> *Acknowledgement of people's fears and reassurance that help is available, right down to local councils checking on vulnerable people in their communities. (Survey respondent)*

However, this does not preclude the need for providers trained in geriatrics and with expertise in mental health, and for mental health services that are inclusive of, and responsive to, the needs of older people.

Supporting the workers who provide care

During COVID-19, community carers expended a lot of energy, time and emotional investment in ensuring that people aged 75 and over were not isolated and had as much contact as possible. Interviewing carers, home care providers, GPs, mental health providers and other frontline staff was outside the scope of this research. However, during conversations with staff from services such as CO.AS.IT., MCWH and the CVS, it became clear that the impacts on workers were immense, and that this could affect service provision.

Workers talked of the toll on their mental health, that the years of the Pandemic had been so difficult that they 'could not bear to think about it and did not want to remember any of it', and there was a personal cost in needing to provide support to consumers:

> *I was often ringing people two or three times a day, and listening to their loneliness, then hearing the same thing from my elderly parents – it was the same thing over and over, day in, day out, and I was worried about how it affected my ability to do my job. (Regional coordinator)*



The state coordinator of the CVS, which arranges volunteer visits for friendship and companionship to people who receive government subsidised essential aged care or home care, described the experience:

> *I think [loneliness] has always been there, obviously, but it was made much worse by COVID-19, much, much worse. And lots of people when they ring me, I would find myself hanging up and having to get up and take a breath and calm down because I would have been made so sad and anxious from their emotion. You know, they'd be crying on the phone and saying just give me anybody and it was hard when we were in such terrible lockdown…, but because Victoria and NSW were the hardest hit, I was receiving literally hundreds of calls in or during that time from people saying 'I don't see anyone. The only person I'm seeing is the person – if they're lucky – that cleans the house and they're too busy to talk to me. I'm not speaking to a single person.'*[44]

A comprehensive Pandemic Response Plan must encompass strategies to support workers and carers; a skilled, professional workforce that delivers appropriate care must also have the capacity to both provide trauma-informed care and receive the support to recover from any vicarious trauma.

5. What helped?

Protective factors are linked to social and economic determinants of wellbeing and health, particularly strong social connections (family, friends, faith based) and financial security

Those who reported that they were coping well during the Pandemic lived independently, with at least one other person in the house, had access to the services and information they needed, including medical, and had digital access. Those that relied on home care and other services continued to receive enough home services and support to maintain their independence.

The importance of strong social connections and engagement was a recurring theme:

> *What helped the most? Sharing the COVID-19 experience with my husband, having a daughter and grandson close by and being part of a very supportive neighbourhood. (Survey respondent)*

> *I had a flatmate/boarder living with me. You [must] acknowledge the importance of friends where people don't have family. (Survey respondent)*

Research undertaken by the National Ageing Research Institute (NARI) has suggested older people who felt well-placed to face this Pandemic had a 'level of financial and social security, with a long-standing network of friends and family'.[45] In our research, nearly 1 in 5 of those who reported their mental health worsened during the Pandemic also reported worrying more about money. While loss of connections, particularly friends or family members, contributed to people's distress, good support networks provided good strengthening and cushioning support:

> *I am 85 and my husband 90. I have a lovely large garden around our villa which, despite extensive pain, I have been able to work in. [From this garden] I can see other residents walking by and have chats. Every day. (Submission)*

> *I am fortunate that I have a background in health, so I know how to look for assistance regarding health matters, also my life experiences have made me quite resilient, I have a very supportive family (although some of them live overseas and interstate) and I have a good private doctor and an excellent psychotherapist who provide the support that I need. (Survey respondent)*

> *I live independently in a retirement village and my husband is a resident in the Dementia unit of the aged care facility, which is under the same roof. I don't think my life has changed very much due to the Pandemic. My mental health and wellbeing weren't affected. I planned my day early in the morning. I planned my meals and if I needed to shop (online). Make a list. I did exercises and made a list of people to contact. Read the newspapers and did the puzzles. Spent time on my computer, engaging with the numerous organisations that I support and also the clubs and charities in which I am involved and my synagogue. There are some TV shows, news, documentaries, and sport that I like to watch. I visit my husband twice a day and feed him his meals. My family contacted me every day. (Submission)*

Others spoke of the Pandemic as an opportunity to learn new things/skills and re-establish connections:

> *I completed the book on my family history and published it. My family members all purchased copies and I have two copies which I will present to libraries, and I feel great about this, and my depression has disappeared. My family also arranged a family night on the 4th of December 2021 to celebrate my wife and my 65 years of marriage. (Survey respondent)*

And of developing confidence and resilience, of learning that:

> *I cope very well with being by myself, partly because my family and friends ring regularly and I have a lovely dog. Because my dog looks so great and is so friendly, I end up talking to lots of interesting people. The physical exercise of walking the dog and playing golf with friends on a regular basis ensures my physical wellbeing and my mental wellbeing. I did psychology in my degree at uni and I think it has also helped. I do mental exercises every day (Luminosity), I read a lot and I enjoy following current affairs, all of which keep my mind active. I live in a lovely unit that has a view of the ocean and I have some very nice neighbours, so this also helps. Although I'm on a part-pension I have no financial worries and I avoid having any large debts. (Submission)*

What did people do to look after their mental health and wellbeing?

According to survey data, these are the strategies that helped people the most during the Pandemic:

73%	Telephone calls with family and friends
64%	Continuing with activities I enjoyed such as gardening, reading
57%	Knowing what to do to stay well and healthy
55%	Maintaining social connections with friends and family
39%	Receiving clear information about the Pandemic, or knowing where to find it
35%	Living with a family member
25%	Having pets

> *Ah, pets! Aged care services and policy makers need to keep front and centre the value and significance of pets. They are not just some kind of cute cuddly thing, but in fact a reason that a responsible adult citizen cares and loves. (Survey respondent)*

The impacts of disrupted social connections, of enforced isolation and loneliness are powerful, recurring themes throughout this research. We know that the impacts of loneliness on older people are particularly destructive, with serious consequence on longevity, and on mental, cognitive and physical health.[46]

People aged 75 and over deployed a wide set of strategies to maintain relationships, stay connected and mitigate the worst impacts. Telephone calls, whether via a landline or mobile phone, were the most important, reinforcing the importance of traditional forms of communication for this cohort of people:

> *If I felt the slightest bit 'fed up', I would ring someone and have a chat. I was in close touch with my small circle of long-term friends so had good contact with them, but for these phone calls I rang people on the outer edge of my acquaintances and was surprised to find how keen some were for a chat. Hearing what they were putting up with, I tended to just listen and count my blessings. This is not to say that I did not get fed up… On occasions I just lay on my bed and shouted swear words at the top of my voice, while I thumped the bed with my arms and legs. i.e., Had a hissy fit. (Survey respondent)*

Many respondents proposed that contacting older people by telephone should be a systemic process, particularly those who were lonely or had a history of mental ill health:

> *Phone calls were my lifeline and I think volunteers might be used by the government to phone people who are lonely and who have no one to talk to. I would willingly give my services as I have always loved tele talk, since I was a telephonist at aged 16. (Survey respondent)*

> *A register of people with mental health so that someone can ring and just see if we are alright, do we need to review the medication, are our partners or support people well and coping. (Survey respondent)*

> *A phone call from a professional of some sort to check on my wellbeing. (Survey respondent)*

For some respondents, technology was a boon, providing a means to stay connected and informed, albeit being a 'steep learning curve' for some:

> *In addition, keeping up contact on a regular basis via Zoom with various activities in which I was involved assisted me in keeping a fairly well-balanced perspective – most days. (Submission)*

I made sure I had contact with at least one other person, usually more than one, every day either by email, phone, text, Skype or Zoom. Either I would initiate the contact, such as making a phone call or setting up a Skype session, or the other party would contact me. This took time to organise and gave me a focus outside my own life. I have kept in touch with the friends and acquaintances I have made through the various stages of my life so had many people I could contact both locally and elsewhere. I also had family members to stay in touch with. It was interesting to hear how people I knew interstate and in other countries were impacted by the Pandemic. (Submission)

Yet for many, digital connections and activities were not possible as the technology was unfamiliar, too expensive, or because it was hampered by slow and unreliable internet connections.

> *When the Village was in total lockdown, the management decided to use Zoom to provide entertainment and activities for the residents. Normally, there are numerous activities every day, but unfortunately there are a few who do not have a computer. (Submission)*

> *There needs to be more recognition that, especially for older people, knowledge and use of 'devices' may be limited, either by lack of knowledge or physical limitations. (Survey respondent)*

This raises questions about the effectiveness of crisis interventions and support strategies that are video based, and warrants further exploration, as has been suggested in international research.[47]

Older Australians whose mental health improved

While the Pandemic and lockdown measures have had profound impacts on the wellbeing of many older people, a small proportion (3%) of respondents reported that their mental health improved during the Pandemic. This is a small sample size and difficult to draw conclusions from.

A more detailed picture emerges when this data is read with the qualitative responses of those whose mental health improved. Those who reported that their mental health improved during the Pandemic lived independently in their own home or with at least one other person in the house. They had access to the services and information they needed, including medical, had digital access and literacy – pointing to the unequal impacts on a diverse cohort:

> *Am fortunate to have a safe home and to be on a pension, rather than trying to keep a business open, pay rent, support children. But sense in the community anxiety and anger, insecurity. (Survey respondent)*

One respondent, living in what she described as a 'comfortable retirement village' similarly spoke of friends and residents who had 'thrived' during lockdowns, as 'everything stopped, people had more time, the cities were quiet' and family members were also less busy, and subsequently more available.

> *Not having to physically go to the GP every month, as I would use my daughter's telehealth phone. My daughter being home more and working at home, so I see more of her. The drought broke so we have done more in the garden and it is looking so good now. (Survey respondent)*

Knowing what to do to stay well and healthy, maintaining connections through telephone calls with family and friends, and having clear information about the Pandemic or knowing where to find it helped them the most over the last two years, as did having pets. They wrote of having time during the Pandemic to understand what 'really mattered', to 'cull unnecessary belongings' and 'declutter' their houses, and of having the resources to pay privately for any services they needed. Reasons for the improvement in their mental health included freedom from commitments, and the ability to plan their days as they pleased:

> *The gift of time and the ability to take life at a slower and gentler pace more suited to my age and the knowledge that one has survived far worse situations and heartache during a long life. (Survey respondent)*

> *I enjoyed being able to wind down and have no commitments at all during the day. I could please myself how I spent the day. I enjoyed the daily walk with my dog through empty, quiet streets. (Survey respondent)*

They also spoke of the advantages of age-related experience and resilience:

> *I felt age gave me an advantage. During my life, at one time or another, I've experienced great loneliness, separation from family and friends, homesickness, illness, lack of friends, both living alone and living with others, and I could go on... So, I thought, 'I've done it before, just get on with it now'. (Survey respondent)*

> *Having to frequently limit going out. Episodes of 'cabin fever'. But I managed because my generation just does. (I am 87). (Survey respondent)*

> *Realis[ing] that even though, as a person regarded as useless, being retired and over 70, I am OK, capable, competent and retaining a great network and a therapeutic sense of humour... (Survey respondent)*

Not all people aged 75 and over were adversely affected by the lockdowns, and some thrived. Having and maintaining strong connections, whether community or family, were the most important protective factors. It was also the most frequently cited strategy to reduce the impacts of loneliness and isolation. These findings are consistent with those 33% of all survey respondents (n=997) who reported they also experienced some positive outcomes from the Pandemic. Again, maintaining strong social connections, support and staying physically well were key protective factors, followed by continuing with activities such as gardening, reading and having pets.

What would help – what older Australians asked for

Below are some strategies suggested by survey respondents:

Find ways that help those who are lonely to connect with people and make sure that those ways do not patronise the elderly.

Easier access to mental health specialists who bulk bill.

Volunteers calling on older people. Meals on Wheels does not give you enough time to check on people. If we can receive Meals on Wheels, then we can receive volunteer visitors.

In home support – maybe a visit from a counsellor to check on my concerns, help from that person to allay many fears that I had and how to deal with my increased temper outburst.

A register of people with mental health so that someone can ring and just see if we are alright, do we need to review the medication, are our partners or support people well and coping.

I would think people living alone and do not have internet or mobile phone or no phone at all would be the most affected and they need to be located and a register kept.

A professional worker to talk to about my sadness.

A support service that checks up on elderly people who live alone, especially the ones who do not have any relatives around.

Acknowledgement of people's fears and reassurance that help is available, right down to local councils checking on vulnerable people in their communities.

Clear, concise medical information with reasons for measures.

Make more provision for the elderly to have care for both carer and spouse.

Priority to be given to aged care visitors supporting seniors to use technology to stay in touch and making it affordable. Focusing on clear information in other languages distributed through community groups. Also, more mental health support in the community.

Someone calling people who live alone.

Contact from a pastoral care provider, without reaching out for support.

Where to from here?

This research aimed to capture the lived experience of Australians aged 75 and over during the COVID-19 Pandemic. It amplifies the voices of a group of Australians whose specific mental health and wellbeing needs are often dismissed. Our sample of older Australians, while one of convenience, has shown that the mental health impacts of the Pandemic and lockdowns were profound for this cohort, may be long term, and require targeted responses and initiatives.

While the NMHC will use this information to improve future pandemic responses, COTA Australia will also continue to advocate for appropriate, accessible and comprehensive services that meet the needs of older Australians.

Appendix 1

Survey aims and design

The survey was designed in collaboration with the Project Advisory Panel, who shared ideas about what questions to ask and what data was needed, and then provided feedback on two drafts. The survey was tested with panel members, and COTA Australia staff for brevity, accessibility and effectiveness.

The survey tool aimed to identify and quantify the:

- proportion of Australians aged 75 and over who experienced mental distress during the Pandemic and restrictions
- proportion of Australians aged 75 and over who did not experience distress or any negative impacts from the Pandemic and restrictions
- most common mental health impacts of the Pandemic and restrictions
- sources of information about the Pandemic and how useful people aged 75 and over found this information
- proportion of people aged 75 and over who sought assistance for their mental health and wellbeing during the Pandemic, and where they sought assistance from
- strategies people used to feel better.

The survey tool was promoted and distributed in mid-January 2022 and ran for four weeks. It was distributed through COTA Australia's membership and promoted through COTA Australia partner organisations. Promotion emphasised that people could choose a telephone or digital survey.

The survey was also scaffolded with information to assist people who may be distressed by participation, and by the impacts of COVID-19 restrictions generally. It contained simple strategies to feel better and protect mental health and provided a list of further resources. This information was developed in collaboration with an external consultant and with guidance from the Advisory Panel. It was also distributed as a brochure at focus groups, hosted online on COTA Australia's website and promoted through the COTA Australia newsletter.

Appendix 2

Who did we not reach?

People in acute psychological distress

This group of people require a different engagement strategy, with serious consideration of the ethical concerns related to interviews.

People who are not connected to mainstream or local services

People who are isolated and see themselves as lonely are difficult to engage. We could not engage with people who were not connected to a service or community group or were not online. We used strategies that relied on our network of committed older people. They received and distributed printed copies of the survey (with stamped, addressed express post packages to send back to us). This network also relied on their regular meeting places and networks. Lockdowns interfered with this.

The original plan was to reach them through informal networks and 'citizen researchers', utilising the interest from some people who checked in on isolated neighbours, who were prepared to interview and connect with them. The subsequent COVID-19 outbreaks and lockdowns made this unfeasible and dangerous. Traditional sources of connection such as libraries also closed. Other sources moved online and saw a marked drop off in participation – for example, Rotary.

Workers employed by community-based organisations also raised the issue of not being able to access those who might be most affected by the Pandemic and lockdown measures. In her report for this research, one worker from the MCWH noted:

> *A few days before the interview, the group leaders got alerts from two of the group's members that they got positive results with COVID-19. Then the leaders sent the messages to the other members. The leaders were about to cancel the group meeting but as MCWH already booked the interview, they kept the group running as usual. But many of the group's members did not come to the meeting. It meant some of them could not join the interview. I have concerns that those ones who cancelled the interview as they were worried about getting COVID-19 might be the ones who got more chances of experiencing distress/stress/worried/sad/anxious, but we could not get a chance to interview them. (Focus group facilitator)*

Veterans

Veterans are a cohort of older Australians that may have been experiencing compounded effects of lockdowns and living with impacts of trauma. It was a key research limitation that we did not capture this information in the survey. Instead, we reached out through our peer consumer organisations who are working with veterans as well as one of our advisory group members, but received no responses for interviews or focus groups.

Where to go for help

Your local doctor or GP is a great place to start for health and wellbeing advice and support. Other support options are available through these telephone services:

Beyond Blue – 1800 512 348 for their Coronavirus Mental Wellbeing Support (counselling support available 24 hours per day, 7 days per week)

Lifeline – 13 11 14 for people experiencing emotional distress (crisis support available 24 hours per day, 7 days per week)

FriendLine – 1800 424 287 (1800 4 CHATS) for a free and anonymous opportunity for older Australians to chat to a volunteer

Carer Gateway – 1800 422 737 for information or support for those caring for an older person

National Coronavirus Helpline – 1800 020 080 for information on COVID-19 or help with the COVIDSafe app (available 24 hours per day, 7 days per week)

Department of Health – https://www.health.gov.au/node/18602/coronavirus-covid-19-advice-for-older-people-and-carers

Beyond Blue – https://coronavirus.beyondblue.org.au/

Australian Psychological Society – https://psychology.org.au/getmedia/97749742-7030-40a0-945e-d91834b418cc/20aps-is-covid-19-public-older-adults-p3.pdf

Endnotes

1 See *Global report on ageism*. Geneva: World Health Organization; 2021, which reports on the 'nature and magnitude of ageism, its determinants and impacts, and outlines what strategies work to prevent and counter ageism, identifies gaps and proposes future lines of research to improve our understanding of ageism'.

2 Based on COTA Australia's original proposal to the National Mental Health Commission and informed by various data sources including feedback from older Australians through various engagement channels.

3 Additionally, two respondents preferred not to identify their gender (0.02 %), 1 identified as non-binary (0.01%) and 1 respondent (0.01%) as transgender.

4 See for example Ferdi Botha, Peter Butterworth, and Roger Wilkins, 'Evaluating How Mental Health Changed in Australia through the COVID-19 Pandemic: Findings from the 'Taking the Pulse of the Nation' (TTPN) Survey' *Int J Environ Res Public Health*. 2022 Jan; 19(1): 558. Published online 2022 Jan 4. Doi: 10.3390/ijerph19010558.

5 ABS Census Population and Housing: Health data summary 2021, Table 1, Type of long-term health condition by age by sex, Health: Census, 2021 | Australian Bureau of Statistics (abs.gov.au).

6 For example, ABS data for 2020-21 shows the prevalence for 'any 12-month mental disorder, by age and sex' decreases with age; 39.6% of 16–24-year-olds compared to 3.7% of 75–85-year-olds had a mental disorder during that period. See Australian Bureau of Statistics, National Study of Mental Health and Wellbeing, Summary statistics on key mental health issues including the prevalence of mental disorders and the use of services, National Study of Mental Health and Wellbeing, 2020-21 | Australian Bureau of Statistics (abs.gov.au).

7 See, for example, Botha et al who found that 'Older adults, those who were unemployed, and those not actively participating in the workforce showed no significant change in distress from pre-COVID levels.' Ferdi Botha, Peter Butterworth, and Roger Wilkins, 'Evaluating How Mental Health Changed in Australia through the COVID-19 Pandemic: Findings from the 'Taking the Pulse of the Nation' (TTPN) Survey Int J Environ Res Public Health. 2022 Jan; 19(1): 558. Published online 2022 Jan 4. doi: 10.3390/ijerph19010558.

8 Australian Institute of Health and Welfare 2022. GEN fact sheet 2020–21 People using aged care. Canberra: AIHW.

9 In 2020, there were 108.7 females per 100 males aged 75-79, 120 females per 100 males aged 80-84, rising to 158.3 females per 100 males aged 85 and over. Australian Institute of Health and Welfare (2021) Older Australians, AIHW, Australian Government, accessed 21 July 2022.

10 Australian Institute of Health and Welfare (2020), Dementia, AIHW, Australian Government, accessed 26 November 2021.

11 Data from 2019 shows that in Australia, Italian (3%) and Greek (2%) were the most commonly spoken languages other than English for people aged 65 and over. Australian Institute of Health and Welfare (2021), Older Australians, AIHW, Australian Government, accessed 21 July 2022.

12 Yulia Furlong, Tanya Finnie. Culture counts: the diverse effects of culture and society on mental health amidst COVID-19 outbreak in Australia. Ir J Psychol Med. 2020 Sep;37(3):237-242. doi: 10.1017/ipm.2020.37. See also Stephanie Dalzell, Government data reveals being born overseas increases your risk of dying from COVID-19 in Australia. ABC Online, At https://www.abc.net.au/news/2022-02-17/abs-data-cald-communities-worse-affected-by-covid-outbreaks/100834104?utm_campaign=abc_news_web&utm_content=link&utm_medium=content_shared&utm_source=abc_news_web.

13 The project has engaged with

- Older Women's Network
- Dementia Australia
- Phoenix Centre, University of Melbourne
- National Ageing Research Institute
- Multicultural Centre for Women's Health
- Family and Domestic Violence Services Victoria
- CO.AS.IT.
- Community Visitors Scheme
- Greek Welfare (NSW)
- COTA Australia members

14 Of the 3 members aged 75 and over, two had formal mental health and trauma training as psychologists, one is employed and one retired. Other members comprised the Community Visitors Scheme State Network Member, ACT, NSW and Victoria and the Coordinator of 'Be someone for someone', an initiative of Feros Care which aims to address the impacts of loneliness on older people.

15 ABS data indicates that 20% of older Australians (aged 65 and over) were born in non-English speaking countries, and 18% spoke a language other than English at home. The most common individual languages were Italian, Chinese (including both Cantonese and Mandarin) and Greek. The proportion who spoke English well or very well decreased with age. These patterns were similar for both men and women. Australian Institute of Health and Welfare. (2021). *Older Australians*. Retrieved from https://www.aihw.gov.au/reports/older-people/older-australians.

16 Australian Institute of Health and Welfare (2022), People with disability in Australia, AIHW, Australian Government, accessed 15 July 2022.

17 There is conflicting research about how loneliness is experienced as people age. Research conducted by the Australian Human Rights Commission in 2021 challenged the stereotype of older people living lives of isolation and loneliness (See What's age got to do with it? (2021) | Australian Human Rights Commission). The AIHW reports that 'Studies investigating the relationship between age and loneliness often have contradictory findings, likely related to differences in study methods and sample variations. Some studies find higher levels of loneliness among older people … while others find lower levels in these age groups,' Australian Institute of Health and Welfare (2021), Social isolation and loneliness, AIHW, Australian Government, accessed 21 July 2022.

18 Roger Patulny and Marlee Bower, 'Beware the "loneliness gap?" Examining emerging inequalities and long-term risks of loneliness and isolation emerging from COVID-19'. Australian Journal of Social Issues. 10.1002/ajs4.223.

19 Murilo Rezende Oliveira, Isabella Pessóta Sudati, Vanessa De Mello Konzen, Ana Carolina de Campos, Lia Mara Wibelinger, Clisman Correa, Fabiano Moraes Miguel, Rebeca Nunes Silva, Audrey Borghi-Silva, 'Covid-19 and the impact on the physical activity level of elderly people: A systematic review'. Exp Gerontol. 2022 Mar;159:111675. doi: 10.1016/j.exger.2021.111675. Epub 2021 Dec 23.

20 Regional health administrator Victoria, in response to callout for project participants, September 2021.

21 Karin Hammarberg, Thach Tran, Maggie Kirkman, Jane Fisher, Sex and age differences in clinically significant symptoms of depression and anxiety among people in Australia in the first month of COVID-19 restrictions: a national survey. BMJ Open. 2020 Nov 24;10(11):e042696. doi: 10.1136/bmjopen-2020-042696. PMID: 33234659; PMCID: PMC7688441.

22 See Burnet Institute and Doherty Institute, The Optimise Study: Gendered differences in coping and responding to COVID-19 Report 6, May 2021; United Nations, Policy Brief: The impact of COVID-19 on women 2020 At https://burnet.edu.au/system/asset/file/4755/Optimise_REPORT6_final.pdf.

23 Multicultural Centre for Women's Health and Gender Equity Victoria, Left Behind: Migrant and Refugee, Women's Experiences of COVID-19 Report, https://www.genvic.org.au/focus-areas/genderequalhealth/left-behind-migrant-and-refugee-womens-experiences-of-covid-19/.

24 Australian Institute of Health and Welfare (2022), People with disability in Australia, AIHW, Australian Government, accessed 21 July 2022.

25 Notes from interview with Esis Tawfik, Victoria and NSW Co-ordinator of Community Visitors Scheme, April 2022.

26 Most people who died in residential aged care from COVID-19 while the survey and focus groups were being conducted were people from Southern European background. Current (July 2022) ABS data now shows that 'those who died of COVID-19 with a country of birth overseas, had an age-standardised death rate close to three times that of people who were born in Australia (6.8 deaths per 100,000 people versus 2.3 deaths), and that those with a country of birth in the Middle East had the highest age-standardised death rate at 29.3 deaths per 100,000 people.' Death due to COVID-19: Country of birth, ABS, COVID-19 Mortality in Australia, Deaths registered to 31 January 2022 COVID-19 deaths that occurred by 31 January 2022 that have been registered and received by the ABS. COVID-19 Mortality in Australia, Deaths registered to 31 January 2022 | Australian Bureau of Statistics (abs.gov.au).

27 Australian Institute of Health and Welfare (2021), Dementia in Australia, AIHW, Australian Government, accessed 21 July 2022.

28 Dementia Australia promoted this project and promoted the survey, but lack of response suggests need for specific research on this cohort. One person responded to call out for interviews, indicated their mental health was unaffected by the Pandemic as they had not experienced any serious lockdown measures (in Perth) and had the requisite support.

29 Australian Institute of Health and Welfare (2021), Dementia in Australia, AIHW, Australian Government, accessed 21 July 2022.

30 Enduring Power of Attorney.

31 One in five (20%) older Australians (aged 65 and over) were born in non-English speaking countries, and 18% spoke a language other than English at home, according to the 2016 Census. The most common individual languages were Italian, Chinese (including both Cantonese and Mandarin) and Greek.

32 Liat Ayalon, Carmelle Peisah, Carlos Lima, Hilde Verbeek, Kieran Rabheru. 'Ageism and the State of Older People with Mental Conditions During the Pandemic and Beyond: Manifestations, Etiology, Consequences, and Future Directions'. Am J Geriatr Psychiatry. 2021.

33 Liat Ayalon, Carmelle Peisah, Carlos Lima, Hilde Verbeek, Kieran Rabheru, Ageism and the State of Older People with Mental Conditions During the Pandemic and Beyond: Manifestations, Etiology, Consequences, and Future Directions. Am J Geriatr Psychiatry. 2021 Oct;29(10):995-999. doi: 10.1016/j.jagp.2021.06.017. Epub 2021 Jul 7. PMID: 34330627.

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39 Jane Fisher, Thach Tran, Karin Hammarberg, Hau Nguyen, Ruby Stocker, Heather Rowe, Jayagowri Sastri, Sally Popplestone, and Maggie Kirkman, Quantifying the mental health burden of the most severe covid-19 restrictions: A natural experiment. J Affect Disord. 2021 Oct 1; 293:406-414. doi: 10.1016/j.jad.2021.06.060.

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